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The book contains 26 essays presented at a 1977 national conference on Implementation of Developmental Disabilities Protection Advocacy Systems. Essays cover the legal and philosophical foundations of protection and advocacy, the management and evaluation of protection and advocacy systems, the training of advocates, resources, and outreach. The book also includes profiles of representative protection and advocacy systems and reports of small group sessions at the conference. (DLS)

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"Implementation of Developmental Disabilities Protection
and Advocacy Systems"

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Implementing Protection and Advocacy Systems

Proceedings of a National Developmental Disabilities Conference

Edited by

Carolyn D. Rude
Linda D. Baucom

Research and Training Center in Mental Retardation
Texas Tech University

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Foreword

A ten-year-old boy spent the day, not long ago, in his father's office. Though he was busy with his books and drawing, he was not unaware of what was going on around him. "When," he asked his father on the way home, "are you going to do all the things you promised to do in your telephone talks today?"

When, our sponsors, bosses, critics, the disabled, and the general public out there ask us, are we going to do the things we confer about?

It has been said that when the Angel Gabriel blows his horn, marking the end of our days in this vale of tears, one-third of the American people will be at a conference, another third will be returning from one, and the remaining third will be boarding planes, driving, or walking happily on the way to attend one. The point is that we spend large sums of money and invest an inordinate amount of time in such meetings as this. As we do a great deal of talking about accountability, it is well to recognize that we too are accountable—to a good number of people and agencies as a matter of fact—but primarily to the people we are pledged to serve, the developmentally disabled. Those who planned this conference were well-advised, therefore, when they decided that the conferees should give attention early on to conference objectives as a sharp reminder of why we are here and how we can best use the time allotted to us.

Like the French who are fond of the kind of exposition that sets forth first what the object or topic being described is *not*, I would suggest that the purpose of this (and most conferences) is not to *preach*, or to *teach*, but to *reach:* to reach, that is, for every bit of information, every good idea, every resource that may help us to do a more effective job of advocacy. To many, the criterion of a good conference is the degree to which they have had an opportunity to express their views; participation is essential, of course, but the kind of participation that shares rather than dominates and that facilitates a mutual learning experience is what is needed.

This conference has been asked to concentrate on implementation—that is, the *how*. The how is highly important and practical but in any discussion of how, the *who* and the *what* are also involved. Let me suggest some general directions or objectives to which we might address ourselves. You have your own objectives in mind, I have no doubt; it will be interesting to see to what extent we are in agreement. First, I suggest we should identify, sort out, and analyze the basic issues that are central to the advocacy function. A sure test of our sophistication and competence in this context is whether or not we can differentiate not only between the trivial or peripheral and the important, but between the important and very important or basic issues. Second, we should wrestle with those issues which affect the advocacy function adversely and discuss how they may be dealt with in our respective communities.

A whole series of questions comes to mind as one begins to consider real issues: (a) How and why has advocacy come to play such a prominent part in the developmental disabilities (DD) movement? (b) Does the movement signal a fundamental weakness in our democratic system? That is, if the system guaranteed rights to all its citizens equally, would a DD movement exist? If there is a weakness in the system, the increased professional and lay concern about what is happening to handicapped persons is an encouraging sign. (c) Finally, how can we, as advocates for individuals who have suffered injustices, relate effectively to the DD councils, which also have an advocacy function? This is particularly important, since the councils have the potential to make an impact on the institutions and agencies serving disabled persons and to help bring about some of the changes that may be required.

The sponsors of this conference have made these very general questions I have raised more specific by asking that we carefully examine: (a) administration, program, and structure, particularly in those advocacy systems that have been in existence for some time; (b) ways of maximizing the financial resources that are available; (c) methods of evaluating advocacy programs; (d) plans for the recruiting and training of professional staff and volunteers; and (e) pending future legislation related to developmental disabilities and advocacy.

In his excellent paper, "Advocacy and the Human Service Delivery System," Ronald Neufeld (1977) made an observation in the final paragraph that underlies the questions I have raised and the mandate given us. "Perhaps," he wrote, "the struggle of advocacy programs, Developmental Disabilities Councils and protection and advocacy systems is part of a much larger struggle."

That "larger struggle," of course, is the effort of a democratic society in the early years of its maturity to give precedence to human need in spite of the complexities of structure, organization, funding, and conflicting priorities. If our advocacy systems are to be of substantial help in that struggle, we had better know precisely what we are doing and how we can do it better. In a very few words, that is precisely what this conference is all about. The opportunity and the challenge are before us.

LEONARD W. MAYO

Reference

Neufeld, G. R. Advocacy and the human service delivery system. In J. L. Paul, G. Richman, & Z. Harvley-Felder (Eds.), *DD themes & issues: A series of topical papers on developmental disabilities* (No. 9). Chapel Hill, NC: Frank Porter Graham Child Development Center, DD/TAS, 1977.

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Preface

In the three short years since protection and advocacy (P&A) systems were mandated by Section 113 of the Developmentally Disabled Assistance and Bill of Rights Act, (DD Act, Public Law 94-103), protection and advocacy for developmentally disabled persons has matured from a vision to a reality. During this period, the Developmental Disabilities Office, of the Office of Human Development, and the Research and Training Center in Mental Retardation, of Texas Tech University, have cosponsored five national conferences to provide the opportunity for P&A planners and implementors to exchange ideas and information. The first conference, in Dallas, March, 1976, was followed by three conferences in the fall of 1976 in Kansas City, Washington, DC, and San Francisco. This volume contains the proceedings of the fifth conference in Cherry Hill, New Jersey, held in December, 1977.

At the first national conference in Dallas, the questions raised by participants and speakers were often philosophical, relating to definitions of protection and advocacy, ideal components of P&A systems, their relationships with DD councils, the role of legal advocacy, and the comparative merits of internal and external advocacy. While some of the questions remain to be answered, the issues are more concrete now; plans are drawn up, systems are functioning. Questions are practical, dealing with funding, the training of new advocates, the uses of litigation, and influencing lawmakers. The visions and the planning continue to be necessary guides to the people charged with implementing protection and advocacy. But with the progress from planning toward functioning, P&A systems are growing rapidly in their capability to fulfill the mandate of the DD Act, to protect and advocate the rights of developmentally disabled persons.

One theme reiterated throughout the Cherry Hill conference and throughout this volume is that protection and advocacy systems cannot succeed in isolation. They need the support and ideas not only of the P&A systems in other states, but of other organizations working with people who are developmentally disabled. The purpose of the conference, and of this volume, has been to put people and ideas in contact with one another and to facilitate the sharing that seems essential to the success of the effort.

Several papers presented at the conference, not included here, are available elsewhere. Miles Santamour has graciously sent conference participants copies of the Airlie House Conference Report and the paper, "The Retarded Offender and the Criminal Justice System." Others wishing copies of either presentation may contact Mr. Santamour at the President's Committee on Mental Retardation, Washington, DC 20201, for information. The substance of Patricia Powell's presentation was based on a monograph by Wolf Wolfensberger, entitled, *A Balanced Multi-Component Advocacy/Protection Schema.* This monograph is available from the Association Resources Division, Canadian Association for the Mentally Retarded, Kinsmen NIMR Building, York University Campus, 4700 Keel Street, Downsview (Toronto), Ontario, Canada M3J 1P3. Shirley Redmond, who spoke at a workshop on programmatic and legal issues central to P&A systems, has available through the Developmental Disabilities Office, 330 C Street, SW, Room 3070-South, Washington, DC 20201, a list of questions and answers regarding evaluation, reporting procedures, and other procedures of implementation.

The volume of proceedings from the conference is organized to suggest the ongoing process of development which P&A systems are experiencing. Beginning with legal and philosophical foundations, P&A systems have moved thus far through formulating state plans (of which four representative ones are described) and to the day-to-day functions of advocacy. As realities have emerged from the visions and plans, so will visions of possible new realities arise from the experiences of implementing protective services and advocacy. Thus, the book ends not with a conclusion, but with a look at the future that can be achieved by the same dedication, energy, and insight that have brought P&A systems this far.

Acknowledgments

The national conference, "Implementation of Developmental Disabilities Protection and Advocacy Systems," and this volume of proceedings were made possible by the coordinated efforts of a number of people.

Jerry Bensberg, Director of the Research and Training Center in Mental Retardation, headed a planning committee that also included Fran Lynch, James Jacks, and Shirley Redmond of the Developmental Disabilities Office, Herb Hinkle and Ethan Ellis of the New Jersey Department of the Public Advocate, and Elizabeth Boggs, Bill Messinger, Marvin Layne, and Anne Farber.

Regional Developmental Disabilities Directors and Associates and state developmental disabilities offices and protection and advocacy systems personnel supplied program ideas and information on projects and resources in their regions. The New Jersey Department of the Public Advocate helped with local arrangements and hosted the conference.

The conference speakers and workshop leaders stimulated thoughtful and lively discussions among participants. Leonard W. Mayo as moderator put the many and various ideas that were expressed into focus. Dayle Bebee, Dennis Bega, Marianne Bennett, Bruce Bernstein, Jack Bernstein, Elizabeth Boggs, Marcia Burgdorf, Keith Carlson, Bob Dublin, Sharon Ellington, Ethan Ellis, Shirley Fritchoff, Lee Henney, Stanley Herr, Herb Hinkle, Martha Hislop, Jennifer Howse, Carolyn Knight, Bill Messinger, Ron Reed, John Rossman, Dan Sakata, Steve Schnorf, Greig Siedor, Lois Simpson, Pat Siuta, Manny Soto, Roger Strand, Joan Strickler, Bob Vogt, and Harvey Zuckerberg helped make the small group sessions productive by serving as discussion leaders and resource persons. Pam Bernanke, Claudia Dickson, Joan Lydic, Darrel Rutherford, Charles Swift, Millie Terrell, and Gay Lynn Testut of the Research and Training Center were recorders at the small group sessions and performed other duties to help the conference function effectively.

Research and Training Center staff have facilitated the publication of the proceedings of the conference. Jerry Parham, Director of Training, generously relieved staff persons of other duties to enable them to work on the volume. Michelle Bush skillfully and patiently typed the manuscripts in their several drafts, Maryann Resendez capably proofread the typescripts and galleys, and Sherry Sancibrian assisted with both editing and proofreading.

All of these persons, and others unnamed, made important contributions to the conference and to the volume, and we are grateful for their assistance.

Part One

Foundations and Concepts

chapter 1

Creating Advocacy Projects for Developmentally Disabled Persons: Rationale and Recommendations

Stanley S. Herr

In coming months, 53 new advocacy organizations will begin the work of securing the rights of developmentally disabled persons. From Guam to Maine, and from Alaska to Puerto Rico, every state and territory has submitted a plan with assurances of an independent advocacy system which will be capable of obtaining legal and other remedies for those disabled persons. Given the unique mandate which Section 113 of Public Law 94-103 poses, that unanimity of participation may in itself be remarkable. Clearly, it demonstrates universal recognition of an unmet need for this specialized advocacy assistance.

During the planning phase, some projects began to provide direct representation for disabled consumers. States now furthest advanced in implementing their Section 113 plans have adopted a clear advocacy model. Those states designated an existing advocacy organization to assume operational responsibilities. Minnesota, Vermont, and New Jersey, building upon the "track records" of well-tested advocacy programs, were three such states. Nor were those states alone in selecting or creating a special unit in an existing advocacy organization to make the Section 113 system move. In Maryland, New York, Colorado, Louisiana, Delaware, Massachusetts, Kentucky, South Dakota and elsewhere, the designated Section 113 agencies were components of ongoing advocacy organizations—Legal Services Corporation field programs, public defenders, public advocacy entities, or nonprofit corporations.

Other states choose to fashion an advocacy system from scratch. Illinois, for example, aggressively pursued various funding sources, sought out grass roots involvement in the planning process, and fashioned a plan of impressive scope and imagination. Rather than recreate elaborate advocacy delivery systems, the Illinois plan is based on contracts to obtain the skilled capability for providing the full range of remedies required by P.L. 94-103. By contract, a consortium of five legal services offices will operate a statewide Developmental Disabilities Law Project. Section 113(a) requires that the designated agency have "the authority to pursue legal, administrative, and other appropriate remedies. . . ." The Illinois plan, like those in other states, recognized the need for some tangible, direct means and capabilities to fulfill these requirements. Implementors of those plans, whether on staff or retained by contract, must be able to pursue those remedies, not simply pursue others to pursue remedies.*

Any advocacy program will hinge not on paper plans or ingenious structural arrangements, but on the energy, imagination, and clearmindedness of its advocates. With many states still in the process of picking their governing or advisory boards, recruiting their advocacy personnel, or determining contracts for essential advocacy services, it is important to review the need for, the right to, and the concept of advocacy embodied in P.L. 94-103. Moreover, by focusing on the rights to be protected and the ethical assumptions and statutory imperatives that guided the statute's framers, form should follow function. This paper also concludes with some recommendations on project goal setting, lessons drawn from literally hundreds of devoted advocates. These advocates aim to provide "nothing less" than the full range of available remedies their disabled clients deserve and require (Knittle, 1977; Mickenberg, 1977).

The Need

> Petitioner is illiterate and mentally defective—a moron or an imbecile. He spent six years in the third grade and left school at the age of sixteen. He has twice been in state institutions for the feeble-minded.
>
> He did not see an attorney until six days after he was first arrested and after he had confessed to the police. During all this time the police questioned him until their questioning produced the confession on which his present conviction is based.
>
> United States Supreme Court,
> 1961 Term (*Culombe* v. *Connecticut*)[1]

The mentally disabled, as our highest court has repeatedly shown, are people legally at risk. In theory, they have the same basic rights as any other American. In theory, they are entitled to supplemental services which a humane society makes available to compensate them for the disabilities afflicted by nature or condition. But there is a wide gap between theory and practice—a gap recognized at all levels of government, from the Presidency, the Supreme Court and Congress, to state and local executive, judicial, and legislative branches.

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*For a fuller discussion of the Illinois plan, see Chapter 8 of this volume.

This decade has seen a new sensitivity to the rights of disabled persons in general, and developmentally disabled persons in particular. But though the direction of change is positive, noncompliance with those rights remains endemic and disturbing. In a recent editorial, the *New York Times* (1977) described the retarded in public institutions and others confined to custodial homes, hospitals, and jails as among "the most vulnerable Americans." "Why," asked the *Times*, "can they not be systematically protected against electrodes or cockroaches or rape?" And those disabled persons residing in the community may be no less vulnerable. The laws designed to prevent their neglect, exploitation or degrading treatment, however, are not self-executing. Advocacy can be the missing link between disabled persons and their fundamental rights and services.

Human rights are only symbolic until someone is prepared to act on them. Pledges of legal and human rights for the disabled, without more, are equally illusory. Advocacy is concerned with asserting those rights, especially for those too inarticulate or infirm to protest shameful deprivations.

Since the capacity to be an effective advocate for oneself or to obtain an advocate is not at all universal, this society has acknowledged its duty to make advocates freely available under certain conditions. Culombe's case, cited earlier, illustrates one of these conditions—when the client is unable to protect his or her own freedom. As the Supreme Court noted in 1961, unlawful detention, a key factor in the Culombe case, "falls heaviest on the weak and illiterate—the least articulate segments of our society."[2] A question posed at that time by Mr. Justice Douglas about the fate of a mentally retarded adult reverberates far beyond the criminal justice system to an entire set of social values.

> If the accused were a son of a wealthy or prominent person, and demanded a lawyer, can there be any doubt that this request would have been heeded? But petitioner has no social status. He comes from a lowly environment. No class or family is his ally. His helplessness before the police when he is without "the guiding hand of counsel" emphasizes the lack of equal protection. . . .[3]

In Culombe's case, the interrogating police officer did not inform the accused of the availability of a public defender. Despite Culombe's obvious handicaps, the officer stated, "It is up to them to mention their attorney."[4]

Since rights can be waived, as the above case exemplified, the developmentally disabled person or someone acting in his or her behalf must choose or take some affirmative step to enjoy a legal right. As Professor H. L. A. Hart (1954) shows in his analysis of legal rights, it is characteristic of laws conferring rights that the exercise of such laws "is . . . dependent on the choice" of the person with the right, or his authorized agent. In other words, some rights are enforceable only upon the right holder's option. Without training the disabled to understand

and exercise those choices or providing them with agents who do, they might as well have no rights at all. Advocacy systems are intended to avoid those injustices and make those rights a reality.

Two further cases illustrate the injustices that can occur when advocates are lacking. Janice, severely retarded and multiply handicapped, had been barred from any formal training from the age of seven. Her father made repeated requests and pleas to the local school system for assistance, but all pleas for his daughter's special education were rejected. When she was 13, a special education official, without consulting any medical records or seeing Janice, determined that the only "program" available would be institutionalization, a step to which her parents reluctantly assented. However, after seeing their child come back on weekends with black eyes, knocked out front teeth, and "blistered and bruised" buttocks, Janice's father "brought her home from Laurel for good."[5] In 1971, Janice, through her parents, joined the class action, *Mills* v. *Board of Education of the District of Columbia,* which resulted in orders that Janice and other children excluded from school have a right to receive a free educational assessment and be provided with a free and suitable publicly supported education.[6]

Consider too the life of Emil Reck, who at 19, had the intelligence of a child between the age of 10 and 11. Originally arrested on suspicion of stealing a bicycle, Reck was held incommunicado for almost eight days without adequate food, counsel, or assistance of family or friends. Subjected to extreme psychological coercion, Reck confessed to murder. He was imprisoned for 25 years, despite the fact that he had long since recanted the confession. In *Reck* v. *Pate,* Reck was described as "never a behavior problem," with no criminal record prior to this arrest, a person classified as mentally retarded throughout his life.[7] Yet, under the cloud of being a confessed retarded murderer, he had been sentenced to a 199-year prison term. As Mr. Justice Douglas observed, Emil Reck's "voice has little persuasion," when in conflict with the word of authorities. As in the Culombe case, "for those of lowly birth, for those without friends or status,"[8] long detention is a recurring practice.

These abuses could have been prevented by the presence of an active advocate. Independent advocates outside the system are needed, not because officials or care providers are commonly antagonistic, ill-willed, or cast in an adversary role, but because there are always limitations to any insider's capacity for helpfulness. The insider may, for instance, define his or her goals in terms such as improving government and maintaining systems, rather than securing the individual's needs and rights. "We've got to have external advocacy," one state developmental disabilities director put it, "because I stop pushing from within at some point." In a similar vein, a superintendent of a leading public institution for the retarded described his facility's program of internal advocacy as "first aid until we get outside advocacy in place." The resourceful advocate will locate and work with such officials to enhance client interest. The aims of client advocacy are manifold, but the underlying purpose is to help the client whose voice may be muffled, and whose rights may be ignored.

Advocacy: A Fundamental Right

There is now widespread acceptance at international, national, state and local levels of the necessity for providing advocates to those disabled persons whose voices may, in Justice Douglas' words, have "little persuasion." While the United Nations Declaration on the Rights of Mentally Retarded Persons requires proper legal safeguards against any unwarranted restriction of rights, the 1975 United Nations Declaration on the Rights of Disabled Persons explicitly states that disabled persons "shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property."[9] In interpreting the 1971 U.N. Declaration, the International League of Societies for the Mentally Handicapped (ILSMH) issued analytical guidelines (1976) for its 42 national member societies urging, among other points:

> Legal representation for the retarded person in any guardianship proceeding (Section 5.2);
>
> The right to the guiding hand of counsel (lawyer) at every stage of a criminal proceeding (Section 6.5);
>
> The assistance of advocates to act on behalf of the mentally retarded person in any proceeding that may restrict the rights of the handicapped person (Section 7.7);
>
> The retarded person's access to a qualified representative (attorney, advocate) whose interests do not conflict with his own (Section 7.8);
>
> Provision of information to the retarded person or representative concerning his/her right to appeal, and legal or other assistance in exercising that right (Section 7.12).

National law and informed opinion call for the creation of advocacy systems insuring the mentally disabled "maximum freedom to exercise legal and constitutional rights and responsibilities" (PCMR, 1976; Bensberg & Rude, 1977; Pool, 1971). Even before the effective date of the advocacy systems mandated by P.L. 94-103, the President's Committee on Mental Retardation had recommended "a nationwide system of public legal advocacy services" with branches in all states. Similarly, the American Association on Mental Deficiency had urged that those retarded persons unable to act effectively for themselves were entitled to an "advocate appointed by the society to protect and effect the exercise and enjoyment" of their enumerated rights (AAMD, 1973).

At the state and local level, study after study has pointed to the need for advocacy programs (Assn. of the Bar of the City of New York, 1962; McCormick, Payne, Smith, & Whitfield, 1971; Pool, 1971). Sometimes judges have raised their voices at the injustices which lack of advocacy fostered. Almost a decade ago, Judge Kenneth Keating, in an opinion from New York's highest court, observed that the due process rights of the institutionalized mental incompetent required a periodic review in which the incompetent is "represented by a person or agency wholly committed to that person's interest."[10] Noting that errors result from even simple inertia, Judge Keating reasoned that further protections were needed.

> When we are dealing with the rights and liberties of thousands of people, the risk of error is too great to leave the correction of errors to family or mental institutions from which may come the abuses. A civilized society cannot do otherwise.[11]

The Concept of Advocacy

It is important to define the concept of advocacy and to indicate its boundaries. In general, *advocacy* means persuasive activity on the part of an individual acting in his or her own or someone else's behalf to secure services that the client wants or requires and to safeguard and exercise the client's rights. Section 113 of the Developmentally Disabled Assistance and Bill of Rights Act, however, establishes a narrow frame of reference: Advocacy involves organizing a system whose mission is to safeguard the rights of developmentally disabled people. The advocacy system acts through an independent core agency designed to meet strict requirements of independence "so that there may be no conflict of interest" (DDO, 1976, p. 1). In representing its clients, the agency must have the capacity to assert and seek implementation of human and legal rights of developmentally disabled persons. Under Section 113, a principal means for accomplishing this is by "representing individuals or organizations . . . on matters relevant to the protection of the legal and human rights of developmentally disabled persons," and otherwise pursuing the full range of legal, administrative and other effective remedies to vindicate their rights (DDO, 1976, p. 11).

The law and its guidelines clearly focus on client-directed advocacy: The advocate is to act for the exclusive benefit of the client or client group and, thereby, accepts a bond of loyalty and trust between him or her and the client. He or she assumes what in law might be termed a fiduciary relationship—"to act primarily for the benefit of another."[12] The lay advocate, whether paid or volunteer, assumes a similar obligation, "representing, as if they were his own, the interests of another citizen" (Wolfensberger, 1972).

These traditional facets of advocacy are already incorporated in agencies operating under state statute or the Legal Services Corporation Act. In that Act, Congress declared that "attorneys providing legal assistance must have full freedom to protect the best interests of their clients in keeping with standards of professional responsibility."[13] Legal services programs in Minnesota and Vermont, for example, have clearly articulated policies of ultimate loyalty to their developmentally disabled clients. Project attorneys attempt to work from the client's assessment of his or her own needs. This client-oriented advocacy stands in sharp contrast to traditional "best interest" postures. Similarly, the Ohio Legal Rights Service, a state agency, operates under statutory requirements that the relationship between legal rights service personnel and its clients be fiduciary ones; that the service be "completely independent" of the service-providing department and attorney general; and that its director be insulated from political interference by a five-year term and removal within that term only for good cause. While independent of the system in which it advocates, the Service has statutory authorization to obtain "ready access" to institutionalized persons and their records so as to "protect and advocate the rights of persons with developmental disabilities." The Service is also to receive and act upon complaints of institutional practices and conditions and to ensure that present or prospective residents are "fully informed of their rights and adequately represented by counsel."[14] "Adequate representation by counsel," as the Supreme Court has noted, "entails active advocacy, not mere impartial evaluation and advice."[15]

Had Congress and the Department of Health, Education, and Welfare not adopted this type of framework, scarce resources might have been dissipated on vague and amorphous enterprises. Fortunately, Section 113 did not intend some bland and diffuse stew, trying to do everything for disabled persons. It is clear that advocacy is functionally distinct from dispensing public information, planning, case management, monitoring, and evaluation, although the advocacy may impinge upon or sometimes contribute to those useful functions. As in the child advocacy field, there are well-recognized hazards in bringing too many disparate functions together under the rubric of advocacy:

> The fact that many of the things sought are at least as important as child advocacy functions does not mean that they belong together in one structure. We believe that experience to date and what is known from relevant organizational and political theory say they do not, and to call everything child advocacy is to blur useful distinctions. (Kahn, Kammerman, & McGowan, 1972)

In framing Section 113, Congress wanted an advocacy system for developmentally disabled persons which could investigate complaints and seek corrective remedies for individuals and classes. It was not interested in an advocacy system that would replicate the planning programs of developmental disabilities councils and other existing agencies which emphasize integration, coordination, identification of unmet needs and promotion of adequate services. As the Senate report put it, the advocacy system was conceived as a mechanism by which a developmentally disabled individual would have the "means to reach outside of the established delivery system for examination of situations in which his rights as an individual citizen may be violated."[16] When a complaint is verified, that examination should be only a prelude to remedial action.

The Rights at Stake

The legal and human rights of developmentally disabled Americans are, of course, as extensive as the rights of any other American. While Section 113 did not single out or limit the rights to be protected under the advocacy system, the legislative history stressed constitutional and other legal rights of the developmentally disabled, expressly citing rights under the Eighth, Thirteenth, and Fourteenth Amendments to the United States Constitution.[17] Senate Report 94-160 emphasized protecting the developmentally disabled from "violation of their human and civil rights." Because of the close juxtaposition of Section 113 with the enumerated rights of the developmentally disabled under Section 111, the Developmental Disabilities Office (DDO) *Interim Guidelines* (1976) reprinted those Section 111 rights in full. Those *Guidelines* stated: "In addition, it is clearly the intent of the Act to provide protection of the constitutional, statutory and equity rights other than the above" (p. 3). The *Guidelines* made clear that the scope of protected rights went well beyond the Section 111 provisions:

> These are *not* intended to serve as the only rights to be safeguarded. DDO views them as *only* some of the fundamental rights of the developmentally disabled—*which are taken to include all* of the rights and constitutional guarantees of all citizens of these United States. (p. 8)

Indeed, DDO *Interim Guidelines* plainly included rights derivative from state citizenship and from other sources. It emphasized that rights of persons with developmental disabilities "must be construed in the widest way to include any legal or other rights which other citizens enjoy, especially the right of due process and equal protection of law" (p. 9).

Though the mandate is broad and inclusive, the resources for carrying out advocacy are scant and must be husbanded. Hence, as the "Advocacy under the Developmental Disabilities Act" report (Herr, 1976) and DDO *Guidelines* recognized, priorities must be chosen to avoid dissipating resources over too wide a range of tasks. The *Interim Guidelines* recommended priorities for representation and case selection, taking account of the case's precedential value, its relationship to a problem attributable to a developmental disability, its implications for basic human rights and constitutional guarantees, and its "involving persons least able to obtain other representation." While more specific priorities and case guidelines await state level assessments by the Section 113 agency staff, prospective clients, and the agency's governing and advisory bodies, there are a number of national factors to weigh in selecting broad areas for direct advocate involvement. Three of those factors are outlined below:

1. Possible correlation with national priorities designated under the 1977 DDO *Guidelines,* which include deinstitutionalization, institutional reform, prevention and early intervention, community alternatives to institutional care, and adult programs.

2. Advocacy assistance available to disseminate information and consolidate recent legislative or policy determinations upholding the rights of the developmentally disabled, including:

   Title II of the DD Assistance and Bill of Rights Act of 1975, especially provisions for least restrictive alternatives and periodic reviews of individualized habilitation plans.

   Education of All Handicapped Children Act, 1975, especially the requirement of surrogates for children without familial support and the right to representation at due process hearings on special educational placement in contested cases.

   Supplemental Security Income (SSI) and Social Security Act provisions, including Medicaid and the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.[18] (For a critique of developmental assessment in the EPSDT program, see Children's Defense Fund, 1977.)

   Rehabilitation Act, 1973, especially the Section 504 regulations issued by HEW Secretary Califano on April 29, 1977, which, in the Secretary's words, call for "dramatic changes in the action and attitudes of institutions and individuals who are recipients of HEW funds."[19]

In these, as in recent advances in state law and policy, full-time advocates are as indispensable as the laws themselves to "help end the shameful national neglect of handicapped individuals and to translate many of their legitimate needs into legal rights."[20] Under the Section 504 regulations, for example, persons with mental retardation, cerebral palsy, epilepsy, and/or a host of other physical or mental impairments are covered by rules designed to end discriminatory practices and provide equal access to facilities and services. Advocates must seek vigorous application of those regulations in order to insure that developmentally disabled people find "open doors" to generic employment, preschool, elementary, secondary, and post-secondary education, health, welfare, and social services.

3. Even with limited staff, Section 113 advocacy agencies need to combine "high impact" and service caseload strategies. Agency advocates should consider the various ways of extending relevant legal precedents to clients within their own states. Among those rights judicially recognized are the:

   Right to counsel in commitment proceedings for mentally deficient persons;[21]

   Right to counsel prior to any "voluntary" sterilization of institutionalized mentally retarded persons;[22]

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Right to assistance of an advocacy agency in administrative reclassification from involuntary to voluntary status;[23]

Right to vote for otherwise qualified mentally retarded persons;[24]

Right to prompt trial, civil commitment hearing, or release for disabled persons detained to restore competency to stand trial;[25]

Right to representation in hearings to suspend or otherwise exclude the handicapped from school, and in special education placement;[26]

Periodic review to insure that long-term residents are placed in the least restrictive setting and that non-dangerous detainees able to survive in safety with outside assistance are released or transferred.[27]

Because these precedents are authoritative or may be incorporated in state or federal law, advocates—through ordinary legal advice and planning for clients—may often be able to negotiate arrangements and rule changes that reflect and advance disabled clients' rights without resorting to full litigation. Too often, the value of declared rights goes unrealized because of the lack of such advice and related follow-up.

Litigation is but one tool for conforming our action to our rhetoric, but it is a tool priced dearly and used frequently by Americans. Developmentally disabled persons have been—and likely remain—far less litigious than the general public. While some administrators may decry the resort to judicial remedy, they cannot deny the benefits it has brought to disabled clients or the public awareness it has fostered in concerning the need for more resources. "Given the fluid state of our society," as Christie (1976) asked, "where else can a person seek reassurance?" Indeed, sometimes developmentally disabled people must enter litigation initiated by others simply to defend rights or benefits previously conferred.[28]

In summary, the compelling priorities for advocacy include issues of deinstitutionalization, education, habilitation and training, residential care reform, community alternatives to institutions, nondiscrimination, and equal access to community services and facilities. No list of possible priorities can be all-inclusive. Depending on its clients' problems, some Section 113 agencies may wish to provide advice and assistance in the areas of due process and fair handling in criminal and juvenile justice settings, privacy, control of property, sexual expression and marriage, employment and income, medical care, state and federal assistance programs, family integrity, community integration, voting, licenses, and other civil rights which are or should be protected by law.

Ethical Assumptions and Statutory Imperatives: Essentials of Section 113 Advocacy Systems

Three interrelated themes underlie the Section 113 advocacy system: independence, pursuit of full remedies, and affirmative outreach. None of these themes is unique to Section 113 agencies; all are implicit in the traditional relationship of advocate to client and the operation of established programs of legal aid and related advocacy assistance.

The independence requirements stem from Congressional acknowledgment that advocates must have undivided loyalty toward their clients. Concomitantly, the designated agency, according to the DDO *Guidelines*, must not only be free of conflict of interest, it must be viewed as such. The advocate's ethical responsibility is to exercise professional judgment "solely for the benefit of the client, and free of compromising influences and loyalties. Neither his personal interest, the interests of other clients, nor the desire of third persons should be permitted to dilute his loyalty to his client."[29]

Providing the advocacy system with the capacity to seek the full range of remedies to redress violated rights is simply an extension of that canon of loyalty to client. Advocates in a Section 113 system have the same ethical obligations to their clients as would conscientious private practitioners to their clients. Those who are represented by the Section 113 agency are entitled to expect at least that standard of advocacy assistance. The full continuum of informal and formal approaches can range from resort to negotiation, informal grievance mechanisms and settlements, internal and external administrative reviews (e.g., special education hearings, welfare hearings, periodic reviews), to appearances in any rule-making, legislative, or court proceeding to protect client interest. In devising a remedy, the advocate's first responsibility is to use the most expeditious method of attaining client ends, thereby conserving scarce resources and avoiding unnecessary conflicts.

Another imperative is the system's responsibility to make affirmative outreach efforts aimed at informing prospective clients of their rights and services available. Affirmative outreach serves both a "prophylactic" purpose (i.e. to offer advice and assistance at some early stage before serious injustice occurs or is compounded), and an equitable purpose (i.e. to devise alternatives to a "first come, first served" policy, which might not provide assistance to those most vulnerable but least able to request advocacy services). Affirmative outreach can include visits to institutions and programs, speaking appearances at public meetings, advertisement of free services, and other presentations and public service announcements.

Some Past Lessons

History is replete with efforts to protect the mentally disabled that have failed or even imposed new constraints on the protected. Planners and practitioners working in Section 113 systems should take considerable care to avoid these pitfalls and enervating detours. Advocacy should not be confused with the

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monitoring and inspectorates of the past. From the eighteenth century practice of having justices of the peace inspect private madhouses, through the rise of Boards of Visitors in institutions, and human rights committees to audit "hazardous" procedures, oversight devices have proven a far cry from client-oriented advocacy (Herr, 1977).

Other useful functions should not be conflated with advocacy. The use of ombudsmen—neutral officers charged with investigating complaints and framing advisory recommendations—offers simply another administrative forum in which to air a grievance. Protective service systems also should not be confused with advocacy. The protective social worker can become a substitute decision-maker armed with coercive powers of intervention and possessing a potential for control which one commentator warns may represent "a dangerous kind of overkill" (Kindred, 1974). Similarly, while coordinating, like monitoring, has its place, it is not the essence of Section 113 advocacy.

The most effective advocacy organizations for the disabled have studiously avoided the strains of assuming multiple and mismatched roles. For example, leading advocacy agencies actually in operation, such as the Minnesota Developmental Disabilities Advocacy Project, the New Jersey Office of Advocacy for the Developmentally Disabled, the Vermont Legal Aid's Developmental Disabilities Advocacy Project, and the Ohio Legal Rights Service, have all clearly adopted a client-representation focus and have each achieved notable gains for their clients and for the developmentally disabled generally (Herr, 1976). In doing so they avoided becoming neutral information dispensers or adjuncts to the planning, monitoring, evaluating, or coordinating process. Instead, they have maintained a coherent identity as advocacy agencies which, in the course of representing clients, may perform a number of training, publication, and informational tasks, but only as an expression of their advocacy role.

Advocacy needs will always far outstrip resources. It is, therefore, essential to develop case management techniques which stress a multi-tiered approach to resolution of client problems. At the first tier are disabled persons who can be self-advocates with suitable information and advice, as well as the relatives, screened volunteers, professional helpers, and other friends of the disabled. The activities at this level include intake procedures, eligibility determination, and basic advice or client referral. Relatively commonplace advocacy problems such as obtaining social security benefits and seeking special education placements can be handled here.

At the second advocacy tier are part-time paid or volunteer lay advocates who have undergone some training in assisting disabled clients to obtain their rights. These lay advocates must be willing to spend a certain amount of time and serve a certain number of clients to make such training cost-effective. They may be recruited from among the staff members and volunteers of associations for persons with epilepsy, cerebral palsy, autism, and mental retardation. In some localities, law schools may have clinical programs for second- and third-year law students who could be enlisted to share an advocacy caseload. Other professional schools, such as social work or education, may also be interested in having their students assist in comparable ways.

The third tier would contain the full-time staff of the Section 113 agency whose legal and other professional advocates would be called upon for specialized assistance and representation requiring greater technical skills, and ongoing commitment of time, or professional licensure. In addition to their representational activities, the core agency staff can augment their effectiveness by training, publishing, and information exchange activities involving other advocates and consumers. That role can best be performed by a core staff which is actually involved in direct representation functions—not in administrative coordination.

Recommendations on Goal Setting

The early stages of planning and organizing an advocacy program can be decisive for the long-range effectiveness of the organization. Based on the experience of existing agencies and the mandate provided by P.L. 94-103 and the DDO *Guidelines*, is is possible to specify some basic elements for creating viable and timely advocacy agencies throughout the nation.

In setting goals and objectives, the largest proportion of staff time and resources should be allocated to client representation.

Prospective clients should have a major role in any policymaking board or body.

In keeping with the ABA Code of Professional Responsibility (1976), the board should set only broad policies and there should be "no interference in the relationship of the lawyer and individual client he serves." (EC 5-24)

All information and advice on the rights of developmentally disabled persons should be provided in terms of an advocacy responsibility to developmentally disabled persons.

The full-time staff of advocates—lawyers, lay advocates, and other professionals—should be selected on the basis of their adherence to the advocacy ethic (i.e., ultimate loyalty to the client), leadership ability, and technical knowledge of law, advocacy techniques, and public policy in developmental disability related fields.

Each core agency should develop an outreach methodology and program for publicizing its services aimed at reaching all segments of the developmentally disabled community.

Each core agency should select some strategic focus and plan for allocating scarce advocacy resources, with a view to addressing urgent concerns sequentially, setting caseloads compatible with good practice, and avoiding duplication of efforts.

To foster coordination and forestall unrealistic expectations, each program should make its guidelines on priorities and caseload limits known to other legal and non-legal advocacy service agencies and the general public.

Each program should formulate evaluation criteria concerning quality of representation and other advocacy services.

Each program should exchange information with advocacy centers having similar goals so that services can be linked, referrals can be made or programs modified to populations with special needs.

Each agency should encourage the training of disabled persons for self-advocacy, and develop basic manuals for use by the disabled persons or those acting in their behalf.

Each agency should attempt to recruit the highest caliber advocates available and give them responsibilities commensurate with their talents and the system's broad mission.

Each agency should formulate plans for attracting outside funds for expanded advocacy services. This will reduce single-source funding dependency and provide advocacy assistance to those unserved or underserved.

Internal reviews, public reports, and periodic conferences should be among the primary tools for evaluating adherence to goals, stimulating organizational self-renewal, and reformulating priorities in light of altered client needs.

Footnotes

[1] *Culombe* v. *Connecticut*, 367 U.S. 568, 638 (1961) (Mr. Justice Douglas and Mr. Justice Black, concurring).

[2] 367 U.S. at 641.

[3] 367 U.S. at 640.

[4] 367 U.S. at 638.

[5] *Mills* v. *Board of Education of the District of Columbia*, Affidavit of A.L.K. May 31, 1971.

[6] 348 F. Supp. 866, 879, (D.C. 1972).

[7] *Reck* v. *Pate*, 367 U.S. 433, 435 (1961).

[8] 367 U.S. at 446.

[9] United Nations General Assembly Resolution 3447, Article 11, 30 U.N. GAOR, Supp. (No. 34) 88, U.N. Doc. A/10034 (1975).

[10] *In re Buttonow*, 297 N.Y.S. 2d 97, 104 (Ct. of App. 1968).

[11] *Id.* at 105.

[12] *Haluka* v. *Baker*, 66 Ohio App. 308, 312, 34 N.E.2d 68, 70 (1941). See also *Kiser* v. *Miller*, 364 F. Supp. 1311 (D.D.C. 1973).

[13] 42 U.S.C. §2996 (1975).

[14] Ohio Rev. Code §5123.94 (1977 Supp.).

[15] *Ellis* v. *United States*, 356 U.S. 674, 675 (1958). See also *Tate* v. *United States*, 359 F. 2d 245, 250 (D.C. Cir. 1966).

[16] Sen. Rep. 94-160, p. 38.

[17] Cong. Rec. S. 9362, 9367 (June 3, 1975).

[18] 42 U.S.C. §1396d (a) (4) (B).

[19] Statement of HEW Secretary Joseph A. Califano (April 29, 1977) at 11. For Section 504 regulations and their authority, see 45 C.F.R. §84 and 29 U.S.C. 794 (1975).

[20] *Id.* at 12.

[21] *Heryford* v. *Parker*, 396 F. 2d 393 (10th Cir. 1968).

[22] *Wyatt* v. *Aderholt*, 368 F. Supp. 1382 (M.D. Ala. 1974).

[23] *In re Buttonow*, 244 N.E.2d 677, 297 N.Y.S.2d 97 (Ct. of App. 1968).

[24] *Carrol* v. *Cobb*, 139 N.J. Super. 439 (App. Div. 1976).

[25] *Jackson* v. *Indiana*, 406 U.S. 715 (1972).

[26] *Mills* v. *Board of Education*, 348 F. Supp. 866 (D.D.C. 1972).

[27] *Donaldson* v. *O'Connor*, 422 U.S. 563 (1975).

[28] *Insurer's Action Council, Inc.* v. *Heaton, Commissioner of Insurance and United Cerebral Palsy, Minnesota Epilepsy League, Minnesota Association for Retarded Citizens*, (defendant intervenors represented by attorneys of the Minnesota Developmental Disabilities Advocacy Project), 423 F. Supp. 921 (D. Minn. 1972).

[29] American Bar Association, Code of Professional Responsibility, EC 5-1 (1976).

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chapter 2

Status of the Developmental Disabilities Program

Francis X. Lynch

In reflecting on the status of the developmental disabilities (DD) program today, it is striking to note how the program has grown over the seven years since its inception with Public Law 91-517. When the program began in 1971, an authorization of about $60 million was proposed to carry out a national program for developmentally disabled persons. The program was to be implemented in every state, serving three groups (persons with mental retardation, cerebral palsy, and epilepsy) at the state level. Developing a state DD plan necessitated bringing together nine state-federal agencies in an intelligent exercise of planning, gap filling, and advocating for developmentally disabled citizens. Shortly after the program was begun, the announcement was made that the appropriation level would be $11 million instead of $60 million. Many people felt that it would be impossible to carry out the mandated program with such limited funds. However, it was not impossible; the basic support program has over a period of time done quite well, and a DD program has been developed in every state.

Similarly, when the DD legislation was up for renewal in 1975, the protection and advocacy (P&A) group was created with massive responsibility and massive expectations. Protection and advocacy for developmentally disabled citizens was needed, and units were to be established at the state government level. These units were to function independently from the government and yet within state government. To enforce this provision of the legislation, some DD money had to be withdrawn from the states, money that they were accustomed to having. Once again, people warned that $3 million could never deal with this kind of a problem or carry to fulfillment the requirements of the legislation. Yet I gather from this group and from the tenor of this conference that we seem to be moving ahead quickly and well in that process.

In the context of that brief historical perspective, my assessment of the current status of DD is that it is doing well. This chapter will explore more specifically a number of matters related to the current status of the DD program, including the special studies undertaken, the DD legislation, and the P&A system.

Special Studies

P.L. 94-103, the Developmentally Disabled Assistance and Bill of Rights Act, mandated the Secretary of the Department of Health, Education, and Welfare to conduct or to arrange for the conduct of studies on the definition of DD, on measures to protect the confidentiality of information on persons with developmental disabilities, and on quality assurance. Another study of interest to P&A people is the annotated bibliography on protection and advocacy compiled through the Research and Training Center at the University of Oregon.

Definition of developmental disabilities. A study of great importance to P&A personnel and others is the *Final Report of the National Task Force on the Definition of Developmental Disabilities,* recently conducted under contract by Abt Associates (National Task Force, 1977). The study recommended that the categorical system for defining developmental disabilities be eliminated and a functional definition be adopted instead. A "substantial functional limitation" would be established when three or more from a list of several classifications of functional limitations applied to a client. The study further recommended that the upper age limit for the developmental period be changed from 18 in the old definition to age 22. A review of this study by Stephanie Mensh (1977) recently appeared in *Developmental Disabilities,* a publication by Morris Associates in Washington that gives a good overview of the DD program.

Confidentiality. This study (Contract Research Corporation, 1977) represents the first step in establishing a national evaluation system, a task assigned to the Developmental Disabilities Office (DDO) by legislative authority through P.L. 94-103. It recommends regulatory language for the administration to use regarding the rights of the clientele for protection. Of particular interest to P&A personnel, it also includes a model state code entitled, "Privacy Act of the Developmentally Disabled," which begins with a description of the right to privacy on which the code is premised. A series of findings is presented, related to potential and existing dangers and the needs of developmentally disabled persons with regard to the use of personal information and privacy rights. Thereafter, definitions of essential terms are provided. Agency responsibility for the contents and use of information services are discussed, including the collection, maintenance, and use of personal information and the individual's rights in this regard. The remaining segments of the report recommend the following elements in a national evaluation system:

Establishment of a state-approved DD review board;

Penalties and remedies for violations of the Act's provisions;

Implementation procedures for the Act's provisions;

Promulgation of rules and regulations;

Procedures for the appointment of representatives of developmentally disabled individuals;

A system of protection and advocacy to be established under the Act.

Quality assurance. These two studies (Government Studies & Systems, Inc., 1978 a, b) were a response to a legislative requirement in P.L. 94-103, which called for an assessment of the existing standards of programs and facilities for developmentally disabled individuals. The DDO staff is currently conducting an evaluation of the studies and their recommendations.

P&A annotated bibliography. An annotated bibliography on protection and advocacy was recently compiled by Anita Chavan (1977) through the Research and Training Center at the University of Oregon. This bibliography could be of value to P&A people.

DD Legislation

The current DD Act (P.L. 94-103) expires in October, 1978. In July, 1977, DDO received word from the Assistant Secretary for Human Development that the administration would likely call for a simple extension of the DD program without substantive changes, either for one or three years. The basis for this posture at that time was that it gave the new administration a chance to study the program.

The Congress responded that it would wait until it had seen the administration's package before initiating legislation or taking other action. This congressional response was somewhat disconcerting, since any legislative packet would have to be before the Congress in May, 1978, in order for it to get into the appropriation and authorization sequences in time.

In October, 1977, Mr. Humphreys, the newly appointed RSA (Rehabilitation Services Administration) Administrator, requested that the DDO staff draft out its perception of needed legislative changes, not only in terms of perfecting the current legislation but also in terms of expanding it. DDO wanted to address legislative matters rather than having the administration respond with a simple extension, and the staff submitted a draft piece to Humphreys in December.

Although at the date of this writing DDO is still in the in-staff working process with this legislative assessment, we have identified several areas of concern.

For example, we believe that the definition and interpretation of the private service provider needs to be clarified in Section 113. Also, Section 111, the compliance section, needs to be strengthened. Our striving to have this clarified in the last version of the legislation was severely modified by the last administration's review of it at the general counsel level. We had interpreted, for example, (as a result of the ambiguity of the DD legislative authority) that we would be able to shut off all transportation funds going into the states. We soon learned, however, that the only funds that could be shut off were the DD funds. Nevertheless, the ambiguity still remains, and the issue needs to be clarified in the upcoming legislative revision.

In regard to money issues related to the DD legislation, another important question arises. How can one expect to mount a program of this importance, of this value, on such limited funds? Certainly this has been an issue since the beginning of the program, as I indicated earlier. There have been three real landmarks in the field of dealing with individuals who are mentally retarded, epileptic, cerebral palsied, and/or developmentally disabled. The first was the development of the parent movement after World War II. The second was the development of the program at the national level and identification at the national level of the program entities—mental retardation, cerebral palsy, epilepsy, and autism. The third is the development of the whole right to treatment/right to education area, in which the P&A movement has been heavily involved. Yet the question continues to arise, "How can we do these things with very finite resources?" DDO strongly shares these feelings. We had hoped that in fiscal year 1978 we would be able to double the program; unfortunately, at the last minute, funds were cut back. Certainly, from the staff level, DDO will continue to strive to increase the funding in the program as well as the ability to get other resources.

In addition to the DDO staff legislative assessment, which will reflect these and other issues, some consumer groups have met recently and developed some legislative proposals and other information for the Congress as well as for the administration. They too are providing input regarding legislative concerns and program direction.

P&A System

Fifty-four states and territories are participating in P&A programs. All but five plans have been approved, and the others are in the negotiating process. As I indicated earlier, the P&A program has a very modest allocation of $3 million nationwide, and the range in state P&A allotments runs from extremes. Sixteen states receive a minimum allotment of $20,000, and seven states receive between $100,000 and $200,000. However, it is encouraging to note that several states have been able to access other resources for P&A. Illinois, for example, has a total P&A budget of $999,000; included in that figure is $200,000 from the DD council and $120,000 in state funds. Georgia is another state with a healthy working budget for P&A; they also receive $200,000 from their DD council. Support from DD councils is helpful but not overwhelming since, to some extent, it represents taking eggs out of the same basket. Nonetheless, it shows an indication of a good deal of interest and involvement. Hopefully, additional resources will emerge as a result of the upcoming legislative renewal process.

As well as gleaning dollars, some of the P&A systems already, to their credit, have found ways to expand personnel. Many have added VISTA lawyers, CETA employees, law students, and social work students to their staffs.

Of the 54 plans, 33 states incorporated new, private nonprofit agencies to implement the P&A systems. A few of the interesting placements are the Texas Bar Association, the University of Alabama Law School, and Puerto Rico's Department of the Public Advocate. New Jersey, with its Department of the Public Advocate, has the distinct honor of having the first approved P&A state plan. This overview of the P&A system makes me feel that even with the limited resources available, this program has moved ahead quite well.

Conclusions

In closing, I heard the unhappy news earlier today that Lady Churchill, Winston Churchill's wife, has just passed away. She was 93 years old and had lived a long and fulfilling life. Thinking of her reminded me of a comment Sir Winston made that I like very much. When Adolph Hitler learned that Churchill was going to be Prime Minister, Hitler said, "Well, we'll wring that chicken's neck." Churchill's response was, "Some chicken, some neck." I think Churchil's attitude fits this particular part of the DD program: The P&A systems are "some chickens" with "some necks." We're moving ahead pretty well, and we have indeed not had our necks wrung. I congratulate you on progress to date and look forward to a continued partnership in future endeavors.

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chapter 3

Federal Legislation Affecting P&A Systems: Where Are We Now?

Elizabeth Monroe Boggs

The Legislative Cycle

The authorization for appropriations under the Developmentally Disabled Assistance and Bill of Rights Act (DD Act, Public Law 94-103) will expire with the current fiscal year, which ends September 30, 1978. This Act, which created protection and advocacy (P&A) systems, was an extension of the 1970 DD Act, P.L. 91-517. The process of passing legislation that will authorize appropriations for P&A systems and other DD programs beyond September, 1978, is lengthy and already well under way, The substantive issues have undergone much analysis and discussion by people who have an interest in the fate of P&A systems. The outcome of the legislative cycle will be affected in part by some political realities that seem to bear only indirectly on P&A systems. The legislative issues relate to, and are impacted upon, by the efforts of the Carter Administration to reorganize the human services system in a very major way.*

Under the Budget Reform Act of 1974, Congress required itself to enact annual appropriations bills before the beginning of each fiscal year. It also stipulated that the funding for any given program can be included in the appropriations bill only if an authorization is tentatively in hand, as it were, about the first of May, and definitively authorized before the October deadline. Thus, if there is to be an extension of the DD Act, the legislation must have been introduced early in 1978, and the hearings must have been held soon thereafter; the responsible subcommittees and full committees must report; the respective houses of Congress must each pass their intended bills; they must schedule and hold a conference to resolve the differences between the two houses; and they must go back to their respective houses to repass the bill, as agreed upon and amended, all before October 1, 1978. We must get to the report stage by May 15. At that time the budget committee must put an appropriate amount in the composite budget resolutions to accommodate the appropriations that are indicated and called for by the substance of the proposed legislation. That is quite a bit to do in a few months.

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*Since many of the situations described in the presentation on December 12, 1977, were transitory, this chapter has been updated to April 1, 1978.

There are people who have been anticipating this eventuality and who are very diligently working on it, both in and outside the government. In anticipation of the legislative cycle, there has been some limited activity within the Office of Human Development Services (OHDS). For various reasons that had to do with the transition into a new administration, there was some faltering along the way. It appears OHDS will recommend a two-year extension with minor amendments. Admittedly, this is merely a holding move to buy time for further consideration of some disposition of the program. Moreover, whereas 20 years ago a Democratic Congress would have paid a great deal of attention to a bill delivered by a Democratic administration, this does not always follow these days. So, it is always important to have something else in your corner.

The new P&A system directors do have friends, both on the Hill and off it. At the moment, Congress thinks of P&A as its own legitimate child, a newborn babe whom everybody is expecting to grow up beautiful, perfect, intelligent, and able. Nothing has happened yet to change their parental expectations. Moreover, the citizen groups that represent the major constituency to be benefited by the P&A program are also very supportive. They are represented in Washington by some very effective and knowledgeable people.

The Work of the Consortium

Beginning in February, 1977, a group of people who got together in Washington, under the rubric of the Consortium Concerned with the Developmentally Disabled (CCDD), began to address seriously the problems which might be encountered in the Act. The members of the Consortium have been working very intensively since the middle of August in an effort to arrive at some consensus about the necessity for changes in the substance of the DD Act and in an effort to bring out a very specific document which could be used as a basis for a bill.

Twelve quite knowledgeable people, representing different components of the DD system, have been working on issue papers, and subsequently, on defining and refining those issues and stating them in more succinct, or enactable, terms. I have not been one of those people. However, I have great respect for the process of analysis and discussion which they have undergone. It behooves all of us to address ourselves very thoughtfully to the recommendations that this group is making and to attempt to use its efforts as a method to minimize our public differences from here on in. There is still time for refinements and a honing of positions, but serious dissension among the constituencies at this late date puts the entire package at risk. This is especially so in view of the fact that some powerful people would like to do away with the DD Act altogether. In fact S. 2600, introduced in February, 1978, by Jennings Randolph, a very influential senator, would repeal the DD Act entirely. We are no longer a motherhood cause.

Even though no one is taking aim right now at the P&A systems per se, I do not believe that these systems would or could have been put in place so widely or so promptly without the cooperation and support of the state councils and the carrot of the formula money allocated in Part C of the DD Act. Therefore, it would be advantageous for P&A directors to recognize their common interest in the Act as a whole, despite their natural and mandated independence.

The Consortium has identified a number of accomplishments of the existing program, such as increasing consumer involvement, demonstrating the need for interagency involvement, providing a focus for advocacy systems, stimulating cooperation among national, state, and local consumer organizations, and financing a large number of productive service, planning, and promotional activities. It also has identified a number of operational problems within the various components of the DD program, particularly the formula grant program. I shall not enumerate these all in detail.

There was one dominant concern, however; the people working within the Consortium agree that "the program has suffered because of a lack of a clear set of national service objectives around which the program could coalesce." Part of the problem arises because, to outsiders, there appears to be overlapping between the target population of the DD program and the target population of other state and federal programs. We (including CCDD) know, of course, that the target population is, indeed, frequently the same; the Act recognizes that. The same people may need one set of services from one agency and another set of services from another agency. Consequently, no DD person belongs exclusively to the schools, or exclusively to the health system, or whatever. Nevertheless, the Consortium (1977) noted that:

> Despite extensive efforts to explain the unique goals of the DD program, many observers—especially proponents of special education, vocational rehabilitation, and maternal and child health and crippled children services—feel that the purposes of the Act duplicate the functions of other major service systems for handicapped children and adults. They point out that authority already exists in such major federal-state programs as Education of the Handicapped Act, the Rehabilitation Act, Titles II, V, XVI, XVIII, XIX, and XX of the Social Security Act, and the Housing and Community Development Act, to finance most of the services to developmentally disabled children and/or adults which are con-

> templated under the Developmental Disabilities Act; if there are deficits in any of these legislative authorities, or inadequate funding levels, they argue, then the proper course of action is to seek additional funds from Congress, and/or appropriate statutory or regulatory changes.
>
> Such arguments appear logical enough on the surface, but they ignore the realities of delivering services at the state and local level, and the historical tendency of all generic service agencies to give lowest priority to clients with the most extensive service needs. Despite recent changes in state and federal laws, there is plenty of evidence that hundreds of thousands of developmentally disabled persons remain unserved or ill served. And there is little reason to expect that this picture will improve if the federal government's only program which focuses exclusively on the needs of the developmentally disabled is eliminated. Nonetheless, an effort should be made to delineate more clearly the service target population of the DD program. . . . (pp. 10-11)

The CCDD, therefore, recommends that there be a clearer statement relative to the service mission of the DD program. There have been numerous statements made in recent years that DD is really for planning and should not have much to do with services. The Consortium is certain that competent planning involving all the various service delivery systems is necessary and should continue under the DD Act. But they also are aware that there are several areas of services that are still not adequately addressed under any of the existing generic or semi-generic federal-state programs. They believe that in the future, a substantial portion of each state's allotment under the state formula grants for DD should be directed into these under-funded service areas; those service areas should be more clearly delineated and targeted so that the anxieties of the maternal and child health people and the rehabilitation people are assuaged.

In the CCDD proposal, plan objectives and funding would be focused (although not exclusively) on a limited number of nationally identified priority areas, with state selection permitted; each state would select among four priority areas. CCDD also proposes that until the appropriation level reaches at least $60 million nationwide, no state should be allowed to focus on more than two at a time. The four areas are: (a) early intervention services for children below age 3, (b) alternative community living arrangements, (c) social-developmental community services for adults, with particular reference to those adults who are not clients of the vocational rehabilitation system, and (d) individual client management service (ICMS).

ICMS is a very misunderstood area, but it has to do with ongoing professional activities of guidance, case monitoring, and follow along, which assist the developmentally disabled individual and his or her family not only to develop but to implement the individual habilitation plan on an ongoing, long-term basis. Most consumers and providers who are in the DD system understand this need well. Implementation of ICMS would support and complement the work of the P&A system.

The CCDD has also recommended that Part D of the DD Act, which authorizes special projects grants, should be somewhat revamped and refocused to support the newly defined service target areas, as well as planning and other activities. One of the three general goals proposed for Part D is support for the P&A system. This is in addition to P&A's own entitlements under its own formula grant in Section 113.

The Consortium strongly supports expansion of the P&A system itself. The basic proposal is that the existing legislation be extended with increased authorization for appropriations. The CCDD recommends $9 million for fiscal year 1979, $12 million for 1980, and $15 million for 1981, with at least a $50 thousand minimum for small states, including the territories. (In response to recommendation from P&A directors, the CCDD in January, 1978, raised the minimum funding figure in its proposal from $40,000 to $50,000.) Basically, CCDD proposes continuation of the DD Act with a tripling of the appropriations and with the possibility that some P&A systems can also receive project grant support for especially creative and meritorious activities. A bill, H.R. 11764, incorporating these ideas, was introduced in the House in mid-March; hearings were scheduled for early April.

Impact of Reorganization

The Carter concept of reorganization will have a direct impact on the outcome of the legislative cycle and on the future of the DD and P&A programs. In a recent speech, Jack Watson, who is a special assistant to President Carter, addressed the American Public Welfare Association (1977). Watson said two things of importance to us. First of all, he expressly instanced the needs of developmentally disabled persons. Second, he talked at some length about the recurring issue of what he called "comprehensiveness versus categoricalness." DD is regarded by many as a categorical program, and there is a lot of opposition to categorical programs. Mr. Watson paraphrased a conversation he said he had overheard Andrew Young having with some young black students. Young said he did not think of integration as producing a society with the characteristics of a soup or puree. Rather, he envisioned a tasty new stew in which you have carrots, onions, potatoes, and nice hunks of beef all immersed in a compatible broth. Watson used Young's metaphor to explain his approach to the issue of comprehensiveness versus categoricalness. If we are smart, we can build on that theme by indicating that, indeed, we may be very small peas in a stew full of large carrots and potatoes, but still that little touch of green is something we do not want to see mashed into a puree.

From 1975 until the summer of 1977, the Developmental Disabilities Office was a distinct administrative entity, reporting to the Assistant Secretary for Human

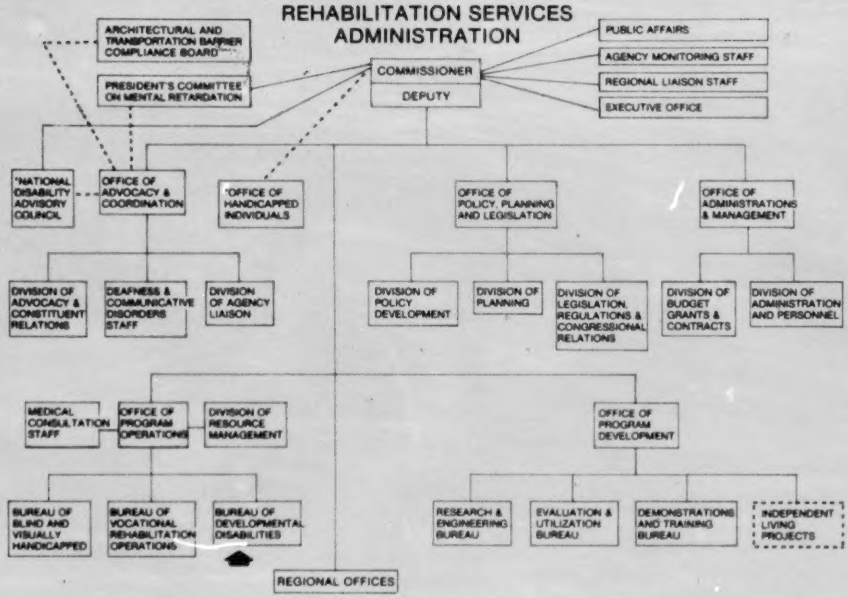
Development. In July, 1977, it was merged into the Administration for Handicapped Individuals (AHI), along with the Rehabilitation Services Administration (RSA), and numerous other units relating to the handicapped, such as the Architectural and Transportation Barriers Compliance Board. In December, 1977, further tentative plans for reorganization suggested that the DD program would be dispersed, with component parts being assigned to their counterparts in RSA. By February, 1978, a new plan was put into effect which maintained the program intact but further subordinated it in the organizational structure (see figure 1). It is as if our pea had become a barely discernible peppercorn. The concept of AHI was abandoned; the whole package is now "RSA."

The Structure of Federal Grants-In-Aid

The future of P&A systems will be affected by funding as well as by the passage of enabling legislation and by federal reorganization. Federal aid to states is distributed through a number of programs. There is federal aid to states for mental health programs, for maternal and child health programs, for social services under Title XX, for vocational rehabilitation, and even a little federal aid to states for developmental disabilities. There is a fundamental structure to all these programs, and it goes like this.

First, there is a formula grant. The formula grant is a grant that goes to the states; any state which files certain applications and conforms to certain requirements is entitled to claim a certain share of the total appropriation. The share is specified by a formula in the authorizing act. In the case of rehabilitation, for example, states are entitled to their fair share of about $800 million. In the case of Title XX, they are entitled to take their fair share of $2.7 billion. The fair share in Title XX is prorated according to the population of each state.

The same piece of legislation that provides for formula grants usually provides for several special project authorities. These are called "discretionary funds" because the federal agency has some discretion about how they are dispensed, as compared to formula grants. Discretionary funds are usually spent in the form of project grants, or possibly contracts. However, the discretionary funds are designed by Congress to support the mission of the formula grants. One component may be designed by Congress to provide training of personnel to be employed by the state or other providers to carry out the activities that the states are funding under the formula grant. The project grants (discretionary funds) also support research and demonstration, technical assistance, and public information. The use of those discretionary funds is subject to creative thinking by the staff in the federal agencies, but the funds do have to be focused in general support of the overall mission set for the states by the formula grant, subject to any other constraints expressed by Congress.


REHABILITATION SERVICES ADMINISTRATION
ARCHITECTURAL AND TRANSPORTATION BARRIER COMPLIANCE BOARD
PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
COMMISSIONER
DEPUTY
PUBLIC AFFAIRS
AGENCY MONITORING STAFF
REGIONAL LIAISON STAFF
EXECUTIVE OFFICE
*NATIONAL DISABILITY ADVISORY COUNCIL
OFFICE OF ADVOCACY & COORDINATION
*OFFICE OF HANDICAPPED INDIVIDUALS
OFFICE OF POLICY, PLANNING AND LEGISLATION
OFFICE OF ADMINISTRATIONS & MANAGEMENT
DIVISION OF ADVOCACY & CONSTITUENT RELATIONS
DEAFNESS & COMMUNICATIVE DISORDERS STAFF
DIVISION OF AGENCY LIAISON
DIVISION OF POLICY DEVELOPMENT
DIVISION OF PLANNING
DIVISION OF LEGISLATION, REGULATIONS & CONGRESSIONAL RELATIONS
DIVISION OF BUDGET GRANTS & CONTRACTS
DIVISION OF ADMINISTRATION AND PERSONNEL
MEDICAL CONSULTATION STAFF
OFFICE OF PROGRAM OPERATIONS
DIVISION OF RESOURCE MANAGEMENT
OFFICE OF PROGRAM DEVELOPMENT
BUREAU OF BLIND AND VISUALLY HANDICAPPED
BUREAU OF VOCATIONAL REHABILITATION OPERATIONS
BUREAU OF DEVELOPMENTAL DISABILITIES
RESEARCH & ENGINEERING BUREAU
EVALUATION & UTILIZATION BUREAU
DEMONSTRATIONS AND TRAINING BUREAU
INDEPENDENT LIVING PROJECTS
REGIONAL OFFICES

*Legislation will be sought to put OHI's functions within the Office of Advocacy and Coordination and to expand the role of the National Advisory Council for the Developmentally Disabled. Until the changes are approved, the Director of OHI will continue to report to the Assistant Secretary.

Figure 1. Organizational structure of RSA

Generally speaking, the various discretionary authorities add up to roughly 10-20% of the formula grant. However, in actual appropriations in the DD Act, the ratio of formula grant to discretionary funds has been about 50:50. About $30 million is available through each part—the DD formula grant (exclusive of P&A) and discretionary funds (special projects plus university affiliated programs of training and demonstration). The special project money includes projects of national significance and project grants administered by the regional offices of the Department of Health, Education, and Welfare. An even greater imbalance exists within the P&A program. Within the special projects authority (Part D), grants are being awarded, nationally and regionally, for technical assistance and other aspects of protection and advocacy which, in dollar total, appreciably exceed the amounts available to the P&A systems themselves through their own formula grant entitlements.

Clearly, the best way to rectify these imbalances is by increasing the state allotments. In the case of the Part C funds, the solution is to raise appropriations; in the case of P&A, the first step is to increase the authorizations, permitting increased appropriations. It appears that there is support in Congress for a three- or four-fold increase in 1979 and after. However, the Carter Administration, which is attempting to limit all types of budget increases, is willing to contemplate adjusting this balance only by trade-offs—that is, by reducing the discretionary grants by approximately the same amount by which the formulas may be increased, or possibly taking P&A out of Part C funds. This is but one more example of the way in which the fate of the P&A system is intertwined with the fate of the DD act and the program as a whole.

Summary

The developmental disabilities program consists of four main parts, of which the formula grant in support of state P&A systems is one part. Legislatively and administratively, the integrity of the program is in some jeopardy. If dismembered, the components would be even more vulnerable. There is little time left to secure renewal of the Act before it expires September 30, 1978. The numerous component constituencies will need to coordinate their efforts if a sound piece of extending legislation is to be enacted in timely fashion.

It is said that the rising tide lifts all boats equally, the small and the large. DD can be a tide, and if the tide rises, it can bear the major parts of the program and the minor parts of the program. However, if the DD community fragments itself and the different components conflict publicly with each other, and if this conflict remains visible in Washington beyond the present time, the P&A systems will probably be the first victims, despite the favorable light in which the Congress currently views the infant born in 1975.

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chapter 4

Advocacy: Toward the Realization of Rights

Thomas K. Gilhool

There has been in this decade an explosion in the assertion of rights by disabled persons. Members of the Pennsylvania Association for Retarded Citizens, after three years of anguished self-examination, came to the conclusion in the early seventies that they would and could turn to the courts to assert the rights of their families and their associates. Two years ago the American Coalition of Citizens with Disabilities and certain chapters of the Easter Seal Society went to court to require the Department of Health, Education, and Welfare (HEW) to issue the regulations governing Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112). That failing, they gathered together this spring from across the country disabled persons to take to the streets of Washington and the HEW headquarters themselves in order to advance the date of the promulgation of those regulations and in order to assure that its content met the full measure of the congressional intention. These are just two examples of the assertiveness displayed by disabled persons in this decade.

If there has been an explosion in the assertion of rights by disabled persons, there has as well been an explosion in duties mandated by law which all manner of public and private institutions serving disabled Americans must fulfill. The duty to provide appropriate individualized education in the most integrated settings possible; the duty to provide access to all services, including generic services, which receive federal funds; the duty under Section 504 of the Rehabilitation Act not only to provide access to those services, but to assure that services are equally effective to disabled citizens as they are to all others; the duty to refit places of work and to redefine work tasks so that disabled Americans may have access to productive employment: These are some of the extensive duties that have been defined as rights of disabled persons have been declared.

What is wanting is not the declaration of rights. What is wanting is their reality. Rights we have in abundance. A civil reality we have yet to create. That is your central opportunity and burden. Congress, in all that it has done in the last five years, has shown itself most responsive to and fully knowledgeable about both the explosion of rights at the hands of the courts and about the assertion of rights by disabled persons themselves. To the senators who wrote the Developmentally Disabled Assistance and Bill of Rights Act (DD Act, P.L. 94-103) against the backdrop of the history of the work of the courts and disabled people and their organizations earlier in this decade, Section 113 has a very simple and clear purpose. It is that developmentally disabled citizens should not be merely one-shotters, but should be repeat players in the game of asserting their rights and in translating them from paper to reality. To come out ahead, they need to be able to stay at the game of the assertion and realization of their rights day by day, month by month, and year by year. That was what Congress had in mind for disabled persons when it adopted Section 113.

Congress, and the American people through the Congress, have offered you an opportunity in Section 113 and have imposed upon you the burden of achieving it. Understanding the objective of Section 113 begins with an understanding of what advocacy is. Advocacy does not refer to someone speaking for another as a guardian. It does not mean speaking instead of another. It may mean speaking in favor of another. The dictionary says an advocate is one who defends, vindicates, or espouses a cause by argument; an advocate is a defender, one who pleads for or in behalf of another. The word's origins are in the Latin *advocatis*—one summoned to help another in a legal cause. Advocacy is the act of pleading for, supporting, or recommending. Advocacy is active espousal

The Six Elements of Advocacy

There are six elements that are central to advocacy. The first element of advocacy is the principal; the second is the advocate. The advocate does not replace the principal but acts at the principal's direction. It is the principal's wishes and needs and the principal's definition of his or her wishes which must guide, direct, and control the behavior of the advocate. Advocacy requires four other things, each of which must be relatively well defined: a forum, a legal rule, an institutional or personal respondent or target, and an objective. An advocate may be of use to a principal only to the extent that the advocate attends to a well-defined forum and brings to bear the law or legal rules against a particular respondent who has breached a duty to that principal. The advocate works that relatively well-defined forum invoking the law against that respondent for particular, concrete, hard goods objectives.

This decade has yielded to us an extraordinarily rich and pregnant array of forums, such as parent conferences, due process hearings, appeals, federal courts, state DD advisory councils, state human relations commissions, and individualized habilitation plans. The Rehabilitation Acts have defined forums in bureaus of vocational rehabilitation. Section 503 of the Rehabilitation Act has created an array of forums, such as the right to negotiate with private contractors for application and for review of policies. Section 504 has similarly created a host of forums. At the top are the several offices of civil rights in the Departments of HEW, the Treasury, Housing and Urban Development, and the Interior. Every recipient of federal financial assistance directly or indirectly from HEW—and there are some 48,000 of them in this country—must prepare transition and compliance plans in consultation with disabled individuals or their organizations. Thus, Secretary Califano has created an extraordinary forum in the Section 504 regulations in which disabled people and their organizations may systematically negotiate and bargain with each and every one of those recipients for the content of those plans and ultimately for the implementation and the realization of Section 504. One goes to these forums, invoking the law, against particularized respondents because the nature of advocacy is not generalized, nor vague, nor random.

Advocacy is, necessarily, hard goods and concrete, and hence, that last element of advocacy, a concrete, hard goods objective, deserves some annotation. It is clear that as the Congress sat to formulate the DD Act of 1974, it did not have in mind anything short of changing the reality for disabled people in particular, concrete, and real ways. Advocacy was not to be an exercise. Their faith (perhaps misplaced), based on their observation of the early years of this decade, was that advocacy provided an opportunity to change results. It is clear in the legislative history of Section 113 that the Congress intended the advocacy system both to secure and to be measured by the product it produced for individual disabled persons (Boggs, 1977). The Congress, as history shows, is not to be satisfied by a process. The Congress chose the process of advocacy because what it wishes to have is hard goods results.

One of the confusions that we trouble much too much with comes from the fact that a necessary element of advocacy is the use of a rule of law. The fact that a legal rule and the use of the law is an element of advocacy does not mean, of course, that only lawyers can play. Perhaps the myth that only lawyers can invoke the law is the product of a profession seeking a monopoly. But there is no area of our national life where the use of the law is solely the province of the lawyer. The use of litigation is simply determined by the situation and the objectives of the principal. Analyzing that situation, one calculates whether litigation or negotiation or legislation or the streets or some combination of them is the means most likely to accomplish the objective.

Interpreting Section 113

The advocacy system mandated by Section 113 of the DD Act is like and unlike other systems and organizations serving developmentally disabled persons. The legislative history of the Act often clarifies what advocacy is and what it is not. Advocacy is not protective services. When the statute uses the word *protect* in referring to the protection and advocacy of individual rights and to a system to protect and advocate the rights of persons with developmental disabilities, it uses the word in the same way that the Fourteenth Amendment uses that word in the Equal Protection clause of that Amendment. There is no indication in the legislative history that the Congress intended protective services.

Similarly, advocacy is not insiders asserting the rights of their clients. It is not bureaucrats, whether in county Mental Health/Mental Retardation systems or in vocational rehabilitation bureaus or inside the government, asserting rights of their clients. Advocacy, as contemplated by Section 113, is not case management advocacy. Of course, to have insiders asserting the rights of their clients is valuable and to be encouraged. My only point is that Section 113 does not authorize you or direct you into that business, except of course, as certain principals might choose as one of their objectives to cause insiders to assert particular rights of particular clients.

Advocacy is not individual education plans (IEPs). Individual education plans and programs are brilliant things. They are honored in Section 112 of the DD Act, and they are honored in the Education of All Handicapped Children Act (P.L. 94-142). We want them and need them. The discharge of the duty to provide IEPs is, surely, a worthy objective of an advocacy system. In particular, a principal using a particular advocate may seek to bring a particular respondent to the execution of that objective. But if we spend advocacy time or money or resources on the design and provision of IEPs, we are not executing a system of advocacy.

Components of Advocacy Systems

A working system of advocacy has four components to meet the different kinds of needs for advocacy. Each of them is a necessary component, and the four of them together are necessary and sufficient components.

Friend advocates. The first component of an advocacy system is a network of one-to-one advocates and principals. These advocates have sometimes been called friend advocates, sometimes citizen advocates. Mr. Justice Stewart, writing for the court in *Donaldson* v. *O'Connor*[1] hinted that the availability of friend advocates may have a dimension above that of choice and that liberty requires that if a person may exist safely in freedom with the help of his family or friends, then the state must allow him so to do. The one-to-one friend advocate, who knows the principal and is responsive to the wishes and needs of that principal, is situated to bring to bear the resources of the other components of the advocacy system at the direction of the principal.

Lay advocates. The second component of an advocacy system is a network of lay advocates. Sometimes they are called citizens advocates, too, and the language is often very clumsy. Lay advocates, however, have more experience with aspects of service delivery to disabled persons than a friend advocate needs to have. Associations across the country, such as the Association for Retarded Citizens, United Cerebral Palsy, the Epilepsy Foundation of America, Society for Autistic Children, or associations for children with learning disabilities, very often have people on their staffs who are specialized in particular subjects, such as education, employment, Supplemental Security Income, or community services. That network of lay advocates is a network of such specialists knowing the institutions and law and the personalities of a particular area and able to bring that knowledge to bear in behalf of the principal, the developmentally disabled individual.

Professional experts. The third component of an advocacy system is a network of professional experts, excluding lawyers. For example, any of you who have experienced a due process hearing to realize the educational rights of a developmentally disabled child know that the presence of an expert in education at that hearing is likely to be the crucial fact in that hearing's outcome. Any of you who have worked extensively in representing and assisting parents in parent conferences, let alone due process hearings, know that the availability of the resources of an expert in education to define the questions and to translate the language of the respondent of the target is necessary; hence, a network of other experts in schooling, in the redesign of jobs, in the redesign of physical settings, or other aspects of service delivery is an important component.

Lawyers. Finally, a network of lawyers is a necessary component of the advocacy system. These lawyers need to be at the disposal of the principals or their associations or organizations full time, both because of the economies of such an arrangement and because if we are to be repeat players at this game and not merely one-shotters, we need to be able to demand the full attention of the people who would work each of the four networks: lawyers, other experts, lay advocates, and the one-to-one friend advocates.

Making a Serious Commitment to Advocacy

It is fair, I think, to say that only the Congress among institutions affecting disabled persons is serious about advocacy. The legislative history of the DD Act of 1975,[2] which must be read closely with the legislative history of the Rehabilitation Act of 1973[3] and of the Education of the Handicapped Acts of 1974 and

1975,[4] shows the recognition, appreciation, and embrace of the modes chosen by disabled persons and their organizations since the turn of the decade. The federal bureaucracy, while equally knowledgeable about the explosion in advocacy, has by and large not chosen to take it seriously. Some $2 million now has been spent over the last five years on the National Center for Law and the Handicapped. The center has not been an advocacy instrument so much as a continuing education instrument. Its funding defied the clear teachings of the experience of the National Legal Services Corporation programs, formerly at the Office of Economic Opportunity. That program did indeed create a network of national backup centers, but the experience with that network showed that those centers were effective because they arose only when there were already around the country some 800 lawyers at work for the beneficiaries of that program. National backup made considerable sense because in the field at home where rights are made or lost, there were people at work. The national backup centers of the Legal Services Corporation teaches something else as well. Poor people were chiefly unrepresented in legal rules made in the fifteenth, sixteenth, and seventeenth centuries. In theory, it was possible to design a national litigation strategy which would change the rules and hence benefit all poor people. The Legal Services program and poverty law experience, by the turn of this decade, suggested that the name of the game was not changing the rules of the law. The name of the game was changing the behavior of rather complex institutions. Hence, litigation was no longer a matter of legal argument. It was a matter of extensive factual analysis. That sort of undertaking has as its necessary condition local advocates posessed of a close knowledge of the facts.

There is still another example, I think, of the lack of seriousness with which the federal bureaucracy by and large has taken advocacy. The Bureau of Education of the Handicapped has had the opportunity to write the regulations under the Education of All Handicapped Children Act. That Act requires parent conferences, due process hearings, and state advisory councils. Yet, nowhere in the regulations is there an explicit permission, let alone an exhortation or requirement, that the funds appropriated by the Congress under the Act flow into the state to be applied to make these mechanisms effective. Advocacy resources are necessary if those parent conferences and due process hearings and the other forums are to work and produce a result for developmentally disabled persons.

The states, I dare say, have similarly by and large not been serious about advocacy. The exceptions perhaps are Pennsylvania, where now some $10 million of Title XX money is devoted to advocacy, and Georgia, which is rather far behind, but still second with some $500 thousand. On the matter particularly at hand, the diverse and, I apprehend, somewhat random nature of the agencies which have been designated to create, maintain, and to run the statewide systems of advocacy raises in my mind the suspicion that among the 50 P&A systems, there will be a diverse and random set of focuses. By and large, the state systems are hobbling at that small appropriation which the Congress made and which has been passed to the states—an indication, I suggest, of the lack of seriousness.

The organizations of disabled people and developmentally disabled people themselves, I think, have not taken advocacy seriously either, certainly not as seriously as the Congress has taken it in Section 113. I had the occasion on Friday at home to do a survey of three of the five national organizations of developmentally disabled citizens. Among those three, including their affiliates, there is some $141 million collected and spent annually. Each of the organizations which was asked how much of it was for advocacy said, "why, all of it, of course." But pressing a bit further, I learned that little of it in reality is spent for the kind of advocacy the Congress has defined.

Lest I leave anyone out, the organized bar has hardly been responsive to the need for legal advocacy, with the exception of the heroic efforts of the American Bar Association Commission on Mental Disabilities and with the exception of the similarly heroic efforts of a great many legal services programs across the country, which have carried most of the legal advocacy of the last decade.

To put that critique in a positive perspective, my expectation is that within the next three to five years, you will see the national, state, and local organizations of developmentally disabled persons devoting some 10% on the average of their budgets to advocacy. For many that will be an understatement. My prediction is that those organizations who most closely reflect the wishes and needs of developmentally disabled people themselves will be the first and will most extensively devote their organizational resources and budgets to advocacy. Where developmentally disabled people have a substantial part in setting the policy of the organization, we can expect that those organizations will increasingly take advocacy very seriously indeed. My models are those organizations of the physically handicapped which are run by the physically handicapped themselves, such as the American Coalition of Citizens with Disabilities and Paralyzed Veterans of America. United Cerebral Palsy (UCP) is, in my judgment, ahead among the organizations of developmentally disabled people in devoting serious resources to advocacy. My own analysis is that this is a product of the fact that increasingly disabled people themselves participate in setting policy at UCP.

What happens with the states, and to some extent, with the federal bureaucracy, depends upon you. There are two necessary conditions. One is that the focus of what you do be clear. Then there must be an addition of dollar resources to the advocacy system. I expect that you will be successful in expanding those resources, and you will be applauded if the focus is straight. For example, the opportunities at your hand include the devotion to advocacy of a significant and substantial portion of the DD Title II formula allocation. The DD Act as a whole must be read as including advocacy among the small number of objectives and modalities which developmental disabilities planning councils are under mandate to pursue. I would hope and expect that some Education of All Handicapped Children Act funds will become available to you. Title XX training funds, to which the ceiling does not apply, should provide the grounds for some significant resources for the advocacy system. Bureau of Vocational Rehabilitation client assistance funds, state funds of various kinds, and funds from professional associations will become available when the demands are articulate and clear. It will not be a very easy job, but the stakes are high indeed.

I know of no other area of national life where the law says all of the right things. With Sections 503 and 504 of the Rehabilitation Act, which gives priority to rehabilitation services for the severely disabled, and with the education acts, we do not want any argumentation. If the central target is a full and free life in the community for developmentally disabled people, as full and free as possible, then we have legal rules and forums very well defined to translate that objective into present reality. Section 504 as a rule opens all generic services to all developmentally disabled people; the education acts give them the same benefits from the education system as anyone else.

The rights are clear. Achieving the realities is the task. In *Watson* v. *City of Memphis,*[5] addressing the experience of the nation after *Brown* v. *Board of Education,* the United States Supreme Court said in words that apply to the rights of the disabled as well as to racial minorities: "The rights asserted here are, like all such rights, present rights; they are not merely hopes of some future enjoyment of some formalistic constitutional promise. The basic guarantees of our Constitution are warrants for the here and now, and unless there is an overwhelmingly compelling reason, they are to be promptly fulfilled."

At your hands, the rights of developmentally disabled individuals may come down from paper to the life of everyday. Mr. Justice Douglas, in perhaps the most poetic of his discourses in contemplation of pending retirement, suggests that present reality is the promise of the Constitution. In particular—and these words resound with respect to people who are developmentally disabled: "The promise of the Constitution to all of America's citizens is independence, the freedom of creativity, and lives of high spirits rather than hushed suffocating silence."[6] Whether and when the promise of the Constitution becomes reality depends now upon what you do with those independent, statewide systems of advocacy to protect and secure the legal rights of developmentally disabled people.

Footnotes

[1] *Donaldson* v. *O'Connor*, 422 U.S. 563 (1975).

[2] See *Hearing Before the Subcommittee on the Handicapped of the Commission on Labor and Public Welfare*, U.S. Senate on S. 427 and S. 458. The Developmental Disabilities Act, Extension and Rights of the Mentally Retarded. Washington, DC: U.S. Government Printing Office, February 8, 1973. See also *Hearing Before the Subcommittee on the Handicapped of the Commission on Labor and Public Welfare*, U.S. Senate on S. 3378, The Developmentally Disabled Assistance and Bill of Rights Act. Washington, DC: U.S. Government Printing Office, May 1, 1974.

[3] See 118 Cong. Rec. 525 (January 20, 1972), Remarks of Senators Humphrey and Percy; 188 Con. Rec. 9495-9498: 117 Cong. Rec. 45974; S. Rep. 93-129, U.S. Code Cong. and Administrative News and 6389 (1974).

[4] See S. Rep. 94-168, Committee on Labor and Public Welfare; 121 Cong. Rec. 10962 et seq. See remarks of Senators Dole, Mondale and Cranston; 121 Cong. Rec. H. 7764 et seq.

[5] *Watson* v. *City of Memphis*, 373 U.S. 533, 537 (1963).

[6] *Papacristou* v. *City of Jacksonville*, 405 U.S. 156 (1972).

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Part Two

Profiles

chapter 5

New Jersey's Office of Advocacy for the Developmentally Disabled

Herbert D. Hinkle
Carol A. Arthur

Following the recommendation of the New Jersey Developmental Disabilities Council, Governor Byrne designated the New Jersey Department of the Public Advocate as the agency to plan and implement the advocacy system required under Section 113 of Public Law 94-103, the Developmentally Disabled Assistance and Bill of Rights Act. The Department of the Public Advocate is a cabinet level agency within the executive branch of government and is unique in the United States. The department has the authority to sue public and private agencies, including other divisions of state government, in matters pertaining to the public interest. The department created the Office of Advocacy for the Developmentally Disabled to take primary responsibility for planning and implementing the advocacy system.

In addition to our Office of Advocacy for the Developmentally Disabled, other programs within the Department of the Public Advocate have the capacity to serve persons with developmental disabilities. For example, the Division of Public Interest Advocacy is empowered to act or intervene in a range of matters affecting the public interest, enabling citizens to challenge governmental actions that may be arbitrary or illegal. The Division of Citizen Complaints and Dispute Settlement takes an ombudsman role in government and handles individual complaints regarding action or inaction on the part of state agencies. The Child Advocacy program represents juveniles in a variety of matters. The Division of Mental Health Advocacy can provide legal representation to indigent persons in any proceeding relating to confinement in a facility providing care and treatment to mentally ill people. Because of the Department of the Public Advocate's experience in serving mentally handicapped and other disabled people, this P&A system quickly became operational.

The Office of Advocacy for the Developmentally Disabled completed its state plan during the fall of 1976. To assist with the planning process, an *ad hoc* advisory committee was established. This committee included representatives from the New Jersey Developmental Disabilities Council, agencies of state government, consumers, and representatives of consumer agencies. While the contributions of this committee as a whole were invaluable, the Office of Advocacy for the Developmentally Disabled is particularly indebted to Dr. Elizabeth Boggs for the assistance she has provided on a continuing basis.

During 1977, the Office of Advocacy expanded its staff and functions by obtaining three additional grants. Thus, in addition to its primary function of providing representation, advice, training, and other assistance to persons in need of an advocate because of a developmental disability, the office now has three other major components. One is a client assistance project, which is funded through a federal grant made to us in cooperation with the New Jersey Division of Vocational Rehabilitation Services. The project assists in resolving problems between handicapped individuals and vocational rehabilitation counselors, other service providers, and private employers. It also serves on a limited basis handicapped people who are not developmentally disabled in one county of the state. The second project, funded by the regional Developmental Disabilities Office of the Department of Health, Education, and Welfare, established an office in New Lisbon State School for the Mentally Retarded to facilitate successful deinstitutionalization of residents from this state facility into the community. This project was undertaken with the cooperation of the New Jersey Division of Mental Retardation. A third grant, awarded by the New Jersey Developmental Disabilities Council, provides funding for staff to research and analyze laws and policies which prevent developmentally disabled people from exercising their full rights as citizens.

New Jersey's P&A system recognizes that litigation is but one way to solve problems in behalf of developmentally disabled persons. The program's staff, which comprises professionals with diverse backgrounds such as law, social work and community organization, reflects this philosophy. Nevertheless, during 1977, the office was involved in major litigation. One case, *In the matter of C.S.* (Hunterdon Cty. Ct. Docket No. HNCC 11-75 April 22, 1977), resulted in the trial court finding that the treatment and care being provided to a 23-year-old, profoundly retarded individual in a state school for the mentally retarded was "shocking and indefensible." The New Jersey Department of Human Services appealed the decision, and the Public Advocate cross-appealed a portion of the judgment denying periodic judicial review of residents at state institutions. The New Jersey Supreme Court has, in an extraordinary action, granted certiorari to review this matter while pending before a lower appellate court (*N.J.*--, Docket No. 14316 February 28, 1978).

Another major case, which was resolved without resorting to litigation, involved assistance to a parents' group in obtaining education and other services which were not being provided to their children by a publicly funded private school. The school was dilapidated and inappropriate for the needs of the handicapped children. As a result of the P&A system's intensive work with the parents to help them understand the administrative process, the parents were able to convince the Mercer County Board of Chosen Freeholders and school officials to establish a new school for their children (see Chapter 13 of this book).

A few other representative activities of the office are these:

> Working with the New Jersey Civil Service Commission to insure that handicapped individuals are not discriminated against when applying for employment with the state;
>
> Participating (in conjunction with the state architect) in the development of barrier free design and regulations for public buildings in New Jersey;
>
> Working with zoning boards and community groups in several communities to promote acceptance of group homes for developmentally disabled people;
>
> Providing technical assistance to groups in four counties to coordinate transportation services for developmentally disabled people;
>
> Assisting parents and developmentally disabled individuals to obtain appropriate services and placements from the New Jersey Division of Mental Retardation, New Jersey Division of Youth and Family Services, and New Jersey Department of Education. The office has successfully assisted in several cases in which there was dissatisfaction with the quality and amount of care, treatment, and education these state agencies were providing;
>
> Working through the civil service system to obtain permanent employment for a mentally retarded temporary employee who, because of an inability to pass a written test, was denied permanent status for over 25 years;
>
> Proposing legislation regarding the licensing and regulation of community residences for developmentally disabled people;
>
> Assisting parents and developmentally disabled persons obtain financial assistance (to which they are entitled because of their disability) from state and federal programs;
>
> Assisting the Department of the Public Advocate with meeting its obligations toward disabled persons under Section 504 of the Rehabilitation Act of 1973;
>
> Monitoring closely the New Jersey Division of Mental Retardation's activities regarding their adoption of standards for intermediate care facilities for the mentally retarded. The Division of Mental Retardation's plan for deinstitutionalizing approximately 2,200 residents of state schools into the community will be closely scrutinized to insure that "dumping" unprepared mentally retarded people into communities without appropriate services does not occur.

Of the more than 180 cases opened by the Office of Advocacy for the Developmentally Disabled during 1977, a large number have been positively resolved to the client's satisfaction on an informal basis. It has been our experience that there is a willingness on the part of most agencies, public or private, to accommodate the needs of developmentally disabled persons once a problem is called to their attention. Thus, a tactful, low-key approach is efficient and saves staff resources for intractable problems, particularly those which would require the agency involved to spend large sums of money to correct the situation.

We have not been able to accomplish some goals set out in our state plan because of limited resources. A year's experience suggests other goals which are not feasible for a program such as ours. During 1978, a permanent advisory committee will be established. Its membership will be similar to the previous *ad hoc* committee, and it will assist us in identifying and reshaping our plan for the next year. To complement the work of this committee, the Public Advocate has commissioned the Eagleton Institute of Politics to survey a random sample of our clients about their attitude toward our program.

The Office of Advocacy has made many outreach efforts. For example, the staff participated in over 70 speaking engagements or training sessions regarding the rights of developmentally disabled people in 1977. Working relationships of various degrees of effectiveness have been established with statewide consumer groups, legal aid societies, and local citizen advocacy programs. This has resulted in the office receiving complaints from all geographic areas of New Jersey and from individuals of each of the developmental disability groups as outlined in the federal legislation. In addition, the office, in conjunction with the Developmental Disabilities Council, has developed and distributed brochures in English and Spanish describing the office and its services. Television and radio spots, coordinated with a public education effort of the council, were also presented.

The Office of Advocacy for the Developmentally Disabled has encountered many of the growing pains as well as the rewarding experiences that confront novel programs. We look forward to meeting the challenges of working with developmentally disabled people in New Jersey.

chapter 6

The Minnesota Protection and Advocacy System for Persons with Developmental Disabilities

Roger O. Strand

Minnesota is somewhat unique among the states in that its developmental disabilities (DD) protection and advocacy (P&A) system was launched in 1973, four years before the federal mandate to create such a system. The planning actually started a year before that, however, at which time the Advocacy and Protective Services Committee of the Minnesota DD Planning Council, during a two-day intensive planning session, established three priority areas for development: (a) legal advocacy—the top priority, (b) citizen advocacy, and (c) residential advocacy.

One of the most difficult dilemmas at that time (1972) was to prove that there was an actual need for legal advocacy services. The University of Minnesota Law School, approached to include the needs of developmentally disabled persons in its curriculum, responded that this was too specialized an area and that the Law School already had enough diversity in its curriculum. The possibility of involving students in problems of developmentally disabled persons via their clinical experiences was viewed positively, however.

The Minneapolis Legal Aid Society (now called Central Minnesota Legal Services, Inc.) approached to provide direct, legal services, was also quite discouraging. Their lawyers were already overworked by trying to meet the legal needs of the poor, the aged, and others. Besides, the Advocacy Committee did not have the facts to prove that developmentally disabled people had widespread or unique legal problems. (There were few, if any, legal advocacy services being provided to developmentally disabled persons in the entire country at that time.) However, through much negotiation and deliberation, a compromise was reached. The Minneapolis Legal Aid Society agreed to supervise a first-year law student from the University of Minnesota to investigate and document the needs. It was a meager beginning, but the Advocacy Committee at least had its foot in the door. The committee was successful in procuring a $1,500 grant from a foundation to pay the student for a summer's work.

To make a long story short, the law student did document the need, and after that one summer, everything seemed to fall into place. In fact, not only did the Minneapolis Legal Aid Society procure a DD grant (not entirely without contention from state bureaucracy) to hire a lawyer and a paralegal person, but a class action suit based on the law student's findings, regarding the right to treatment—*Welsh* v. *Likins,* 373 F. Supp. 487 (D. Minn. 1974)—was also set into motion.

As an aside, this case was only recently settled out of court after four years of contest. This action may result in procuring additional appropriations from $11 to $14 million a year for state hospital staff and physical improvements.

Another accomplishment resulted from our initial efforts. The University of Minnesota Law School did develop a seminar on developmental disabilities.

On April 20, 1976, the Governor of Minnesota designated the State Planning Agency to plan and implement the Minnesota DD/P&A system. The State Planning Agency is an independent agency in that it does not provide any direct services to persons with developmental disabilities, thereby avoiding conflict of interests. The actual advocacy services—for example, legal and citizen advocacy—are provided by other agencies under contract with the State Planning Agency. These contract agencies are also independent in that they do not provide any treatment, services, or habilitation to their clients, other than through their prescribed role as advocates.

The State Planning Agency currently contracts out for three projects: one statewide legal advocacy service and two local citizen advocacy demonstration projects. The Minnesota Developmental Disabilities Legal Advocacy Project is a separate project within the legal aid office, Central Minnesota Legal Services, Inc. Its staff of four attorneys and one paralegal is supported by 200 volunteer lay advocates throughout the state. In addition, a Duluth Branch Office is staffed by one attorney and one paralegal. The project's advisory committee includes nine members, representing consumer groups and professionals. An average of 250 persons are served per quarter. The two citizen advocacy programs, under contract, are located in Duluth and Minneapolis. In Duluth, operating out of the Duluth Association for Retarded Citizens, special emphasis is placed on the development of leisure time opportunities in the community to support the expressive citizen advocate/protege relationship. About one hundred volunteers have received training and have been matched with their developmentally disabled friends.

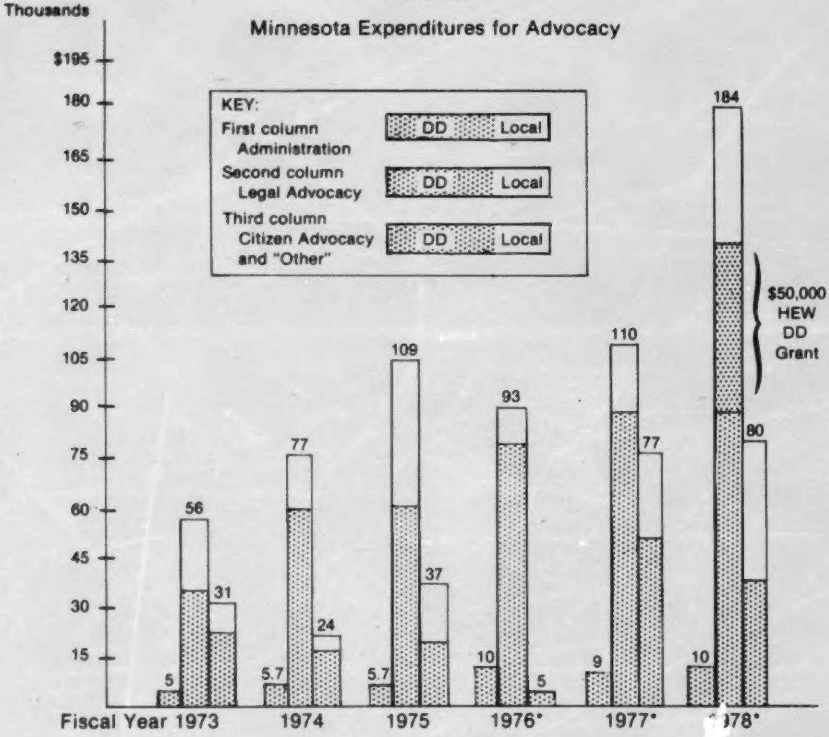
The CADRE Project in Minneapolis, administered by Reachout Today, Inc., will be recruiting and training volunteers to serve as instrumental citizen advocates for developmentally disabled persons who have become involved in the criminal justice system as offenders or victims.

There are several other citizen advocacy programs, not DD-funded, in Minnesota. Efforts will be made to develop interagency agreements with them so that they can be considered as part of the P&A system.

Table I shows the amounts spent on advocacy in Minnesota over a six-year period. There has been a substantial, long-term financial commitment to P&A on the part of the State Developmental Disabilities Planning Council. The method of contracting for services has allowed for reasonably low expenditures for office administration ($5-10 thousand per year), leaving more for the provision of direct services to clients.

TABLE I

Minnesota Expenditures for Advocacy



*DD portion includes both state DD formula grant and protection and advocacy (Title II) funds.

Many other agencies, both public and private, provide one type of advocacy or another on either an individual or collective basis. Fifty such state agencies and organizations have been identified. For example, there are residential advocates in each of the state hospitals through a program administered by the Department of Public Welfare. Other organizations include the Division of Vocational Rehabilitation Ombudsman Project; the Nursing Home Ombudsman Program located in the Council on Aging; the Department of Human Rights; and the PACER Project (Parent Advocate Coalition for Educational Rights).

The need for coordination and cooperation among these separate groups is indeed striking. Our legislature is currently looking at ways to avoid duplications and to improve coordination in the entire advocacy field. A structure similar to New Jersey's is not at all unlikely for Minnesota's near future.

From our experiences, we have learned several things that we can share.

1. The consumer groups are the cornerstone of a successful P&A system. No one can tell the story of the needs of developmentally disabled persons as well. Without their voice, the entire process is slowed down or almost impossible.
2. Contracting for legal services and for demonstrating innovative approaches to other types of advocacy (for example, youth advocacy) does result in providing direct advocacy services as well as in paving new paths for the future.
3. The method of contracting also seems to make the best use of what small amount of money is available and puts most of the dollars directly into services without the high cost of overhead involved in doing it yourself.
4. Utilize and build upon existing resources as much as possible. Duplicating wastes time, energy, and money.
5. Do not come on like gangbusters! Most providers really want the best for their clients. Let them know that you can help them to do their jobs better and that they are important people. Advocacy in this light should not be a threat.
6. Remember that the goal of advocacy is not to do *for* another person, but rather *with* the person and ultimately to allow the developmentally disabled person to do for himself or herself and act in his or her own behalf. When this happens, we will not need outside advocates so much.
7. Last, but most important, planning does pay off. You cannot possibly do everything at once. By concentrating your limited resources on your top priority, you can accomplish your aspirations step-by-step. Time and patience are your allies for moving onward.

chapter 7

The Minnesota Developmental Disabilities Legal Advocacy Project

Patricia A. Siuta

Minnesota has had a Legal Advocacy Project since 1973. It is a statewide project, that has provided comprehensive legal services to developmentally disabled persons. The project's services include direct representation of clients, drafting of legislation and regulations, training of lay advocates, preparation of informational materials, supervision of law students in clinical programs, and much speaking on the legal rights of developmentally disabled persons.

At the outset of the project, an announcement of the project and the services it provided was mailed to all identifiable consumer, professional, and governmental organizations and agencies in Minnesota. Project staff also met with members of the Minnesota Associations for Retarded Citizens, Minnesota Epilepsy League, and United Cerebral Palsy of Minnesota to determine which legal issues concerned consumers. The project has continued to have a close relationship with each of these consumer organizations, and this has been a critical factor in the project's success.

The project's initial caseload was relatively light. The project staff during the first year conducted a thorough review of all relevant legislation, and from this, developed a training manual for advocates, covering all substantive laws affecting developmentally disabled persons. This manual was used in intensive training of staff, key volunteers in consumer groups, and other advocates. The manual, called *Legal Rights of Developmentally Disabled Citizens in Minnesota*, has been updated every year and is available from the project.*

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*Copies of the manual may be obtained for $1.50 from Legal Advocacy for Developmentally Disabled Persons, 501 Park Avenue, Minneapolis, MN 55415.

After completion of the intensive training of staff and volunteers and the development of training materials, project staff suggested that selected members of consumer organizations throughout the state be trained as paralegal advocates. With such training, the members could serve as advocates within their communities and increase the impact of the Legal Advocacy Project. Since our project was statewide, and since at this time, the staff included only one attorney and one paralegal, training paralegal advocates was really quite a job. The advocate training was provided to members of consumer groups and had several important indirect results. In addition to promoting development of local leadership in the consumer groups and acquainting project staff with local contacts, it has been an important source of new cases for the project.

By the end of its first year, the project carried approximately 70 cases. In addition, the project had compiled detailed training materials covering most of the laws affecting developmentally disabled individuals in Minnesota. The project trained the staffs of the three consumer groups, trained some 200 interested consumers as paralegal advocates for their communities, began the drafting of major legislative changes, initiated an outreach program through speaking appearances and meetings with consumer groups, and, finally, started developing a resource center of materials on the legal rights of developmentally disabled persons. These activities were all accomplished by a staff of one attorney and one paralegal.

In its second year, the project developed a pattern of activities which has continued to exist. Project staff concentrated their efforts in three principal areas: direct representation of clients, legislative and regulatory advocacy, and consumer education and advocacy training. The majority of project time is spent on direct representation of clients. The project operates on the philosophy that the client's legal needs should be met as quickly and efficiently as possible. Project staff first try to resolve a person's problems informally and resort to litigation only when staff cannot accomplish the client's objectives with a speedier method. Legal services are provided by the project without charge: People are eligible if they have one of the disabilities and if their legal problem is related to their disability. Thus, staff members do not usually represent developmentally disabled persons in obtaining a divorce. The staff tries to work only on cases that have an impact on disabled persons and that arise out of that disability. The project normally carries a caseload of several hundred cases, covering a wide array of problems. The most common problems include special education, release from institutions, guardianship, restoration to capacity, zoning of community residential facilities, institutional conditions, minimum wage claims, discrimination, and social security and other programs of financial assistance. The project has never turned down a case of an eligible client.

Any project advocating in behalf of developmentally disabled people will, of necessity, devote substantial energy to advocacy. Laws affecting mentally retarded and other developmentally disabled people are frequently antiquated, overly restrictive, discriminatory, and offensive. This was certainly true in Minnesota. Over the years the project has drafted and helped achieve revisions of state laws on guardianship, sterilization, marriage, adoption, voting, zoning of residential facilities, and civil commitment. The project has been active in the development of many state regulations affecting handicapped individuals.

The success of the project is attributable in large part to our close contact with consumer groups. Consumer group representatives are on the project's advisory board and consistently meet with project staff to discuss project activities and priorities. Project staff persons draft legislation and regulations only in close consultation with consumer groups directly affected by the proposed legislation. We are philosophically committed to the principle that our only duty is to our clients and that we should not substitute our judgment for what the client wants.

chapter 8

The Illinois Network of Area Advocacy Projects

Stephen B. Schnorf

Illinois began its planning process for the protection and advocacy (P&A) system as many states did. The governor designated the state planning council on developmental disabilities as the agency responsible for planning our P&A system. We identified four things to consider in our planning process: federal guidelines, consumer input, funding, and political realities. Identifying federal regulations in Section 113 of the Developmentally Disabled Assistance and Bill of Rights Act (DD Act, Public Law 94-103), and then the *Guidelines* issued by the Department of Health, Education and Welfare pursuant to Section 113 (1976), such as requirements for independence or requirements to be conflict-free, that we be able to pursue legal as well as administrative and other remedies, and that we have a statewide capability, gave us a foundation for knowing what was expected of us by the people who had established this legislative or statutory requirement. We invested a great deal of time and effort in establishing and maintaining a dialogue with consumer groups around the state to learn what the citizens of Illinois perceived as advocacy needs and how they wished to see those needs addressed. Planning on funding was to determine how we were going to pay for the P&A services. The political realities that we considered were the politics in our consumer movement and partisan politics. We went through an election and a changing of administration during our planning process and had to reestablish a new set of contacts with a new administration. This caused a four-month period when we were operating very much in a vacuum with no one to relate to; it caused us a lot of trepidation. In the whole planning process, we had very strong support from our state developmental disabilities (DD) council and from our state Association for Retarded Citizens. We also were fortunate that we had good support and assistance from our regional DD office.

In terms of a conceptual model, our plan calls for our state Developmental Disabilities Advocacy Authority to be an agency that elicits, facilitates, and provides resources for the development of consumer owned, operated, and controlled advocacy services. We do not perceive our state authority as providing direct, individual case representation for developmentally disabled persons. We are moving toward the creation of a statewide network of area advocacy projects—projects that will be funded by the state authority. These projects would be locally owned and operated, based either in already existing or specially created not-for-profit corporations, that would agree to assume the responsibility on a local level. A local level might range from a township—perhaps in the Chicago area with a couple of hundred thousand people—to a region downstate with several counties, but about the same number of people. There the advocacy projects would agree to assume the responsibility for meeting the advocacy needs, with the exception of legal remedies, of the developmentally disabled people who live in that region. Advocacy projects would agree to assume the responsibility for insuring the right to a public education and would agree to assume the responsibility for providing or arranging direct assistance to clients and their families in pursuing administrative and other nonlegal remedies.

The process is a very open-ended one. The consumers in Illinois, believing that there is not a system that works equally well everywhere, wanted a process that would allow each community to design for itself the approaches that would best meet the advocacy needs of the developmentally disabled people who live in that area. Thus, the function of the state authority is to provide the funding and the technical assistance to a local group that wants to develop a direct advocacy service in their area. We have developed requests for proposals, encouraging groups to submit proposals to become an advocacy project for their particular area of the state. We know that we will get many different models for proposals. Some groups, for instance, will propose using our funding base to create a network of citizen advocacy projects, while one will propose a relationship with a state university school of social work, contracting for graduate interns to provide P&A efforts in behalf of, or with, developmentally disabled people in their particular area.

We have a funding reality to face. We will not be able to network the whole state with area advocacy projects in the first year or two. Our planning calls for funding three or four such projects a year. On that basis, it will take us approximately five years to network the whole state with area advocacy projects. In the interim, we feel responsibilities to provide assistance to persons who live in an area where there is no area advocacy project. In that case, we intend to operate a P&A effort at the state authority level. That P&A effort will be available through approximately eight staff persons spread around the state, to provide demand-response advocacy services for people living in a part of the state where there is no area advocacy project. As we cover the state with area advocacy projects, that effort will be phased out, because we do not want the authority at the state level delivering direct advocacy services.

In order to have the capability of pursuing legal remedies, Illinois will contract with five legal assistance foundations that together cover the state of Illinois with approximately forty law offices. The legal assistance foundations will then operate as a consortium which we will refer to as a developmental disabilities law project. One advantage to this approach is that we will avoid duplicating law libraries and offices. We will fund the legal assistance foundations for the direct cost of eight new full-time attorneys, who will specialize in and devote 100% of their time to the legal rights of developmentally disabled people in this DD law project. Those eight people will be spread out around the state of Illinois so that every legal assistance foundation office in Illinois will have access to one of those attorneys, either as a specialist, or to take on cases directly. The work of the attorneys will focus on definitions of clients' rights and liabilities and interpretations of laws. At some point in the process of pursuing a resolution of a problem, a law project attorney might step in to directly represent a client in an administrative hearing, or if necessary, in litigation. We also expect the law project to impact on the legal education system in Illinois, both through our law schools and through a continuing education program. Finally, the law project agrees to participate in the statutory and regulatory lawmaking process, through expert testimony, and through the drafting of model legislation or licensing standards.

Through the state authority we are going to operate an institutional advocacy project. Through this project, at least one advocate who is on the state advocacy authority's payroll will work full time in each state-operated residential facility serving 100 or more developmentally disabled persons. There are 12 such facilities in Illinois right now. The facility will agree to provide office space, telephone, and access to clients' records, within the limits the law allows. The advocates will function in three different capacities. One function will be direct representation of the clients who live in those facilities. The second will be the training of staff of those facilities in the rights of the residents who live there. The third will be working as assistants and resources for existing advocacy entities within those facilities, such as parent groups and human rights committees, helping them to become more effective in advocating for the rights of the residents of the facility.

Illinois undertook a great deinstitutionalization program in the 1960s. In a period of less than ten years, we reduced by half the number of people in state hospitals and developmental centers. Unfortunately, as a result, we created a whole network of proprietary mini-institutions around the state. We now have about 12,000-15,000 residents of community programs, such as sheltered care homes, nursing homes, and skilled care facilities, of whom more than half are developmentally disabled persons who used to be residents of state operated institutions. Generally, the responsibility for advocacy for and with developmentally disabled people living in community residential programs is the responsibility of the area advocacy project in the area in which that facility is located. In reality, we know it will take us a long time to cover the state with area advocacy projects. We know also that providing advocacy services in a multitude of settings will consume resources voraciously, whether the services are provided at the state or local level. In order to address that problem, we have a project to train the parents of people living in private residential facilities, or other interested citizens, in how to be effective monitors and advocates for the quality of service that their children and other residents of those facilities receive. We are in the process of developing training curriculum, which we will field test before undertaking a full-scale training project. We hope to train 200 or more parents each year, providing them with information regarding the rights of residents and licensing and regulatory standards that are applicable to the facility. In particular, we will train them in the development of individual care plans and how to use these plans as a tool with which to measure and impact on the quality of care that is being received by their son or daughter or other residents of the facility.

Illinois faces some challenging problems, especially in the five-year period while we work toward fully implementing our P&A plan. However, by maximizing consumer input into the P&A system through area advocacy projects, and by assisting those projects through the state advocacy authority, we hope to develop a P&A system that will meet a diversity of needs held by a diversity of clients.

Reference

Developmental Disabilities Office, Department of Health, Education, and Welfare. *Interim guidelines for development and implementation of a system for protection of the individual rights of and advocacy for persons with developmental disabilities.* Washington, DC: Author, November 1976.

chapter 9

The Louisiana Protection and Advocacy System: Placement Within a Legal Services Corporation

Lois Simpson

The Louisiana protection and advocacy system is housed within a legal services corporation. During the planning phase of the Louisiana protection and advocacy (P&A) system, several options for placement of the system were reviewed and considered: placement in the Office of the Governor, placement in an existing private nonprofit agency, the development of a consortium made up of the four developmental disabilities, and so forth. The advantages and disadvantages of each option were duly considered, with the outcome being a consensus for placement in an existing private nonprofit agency. It was felt that such placement had the advantages of saving the system dollars and of maintaining the greatest degree of independence from government.

Once it was determined to place the system in a private nonprofit agency, the next task was to find one that had both the willingness and the capability to house the system. We looked for an agency with experience in the advocacy field which could be used to the advantage of the P&A system; and, of course, we looked for an agency which could offer the system funds to augment the minimal federal contribution. In the New Orleans Legal Assistance Corporation (NOLAC), we found not only these two attributes but others as well.

NOLAC, which has been in existence since 1968, has nine years experience in legal advocacy for the poor, and its target population (the four parishes included in the greater New Orleans metropolitan area) includes one-third of the total developmentally disabled (DD) population of the state. Although NOLAC exists solely to serve the indigent, we felt that many of the problems affecting the poor and the techniques used to solve such problems are similar to those applying to the DD population. Thus, we felt we could depend on the expertise of NOLAC attorneys to a large extent.

NOLAC also has the advantage of being the oldest and largest legal assistance corporation in the state of Louisiana. Thus, it often assumes the role of mentor to the other six legal assistance corporations around the state. We felt this relationship would help us in our efforts to train public interest lawyers throughout Louisiana.

Another advantage of placement in NOLAC is the fact that NOLAC also houses a legislative advocacy unit from which we were assured on-the-spot technical assistance in our legislative activities. And, finally, NOLAC offered to supplement our budget by 10%.

These were the major advantages planners saw in placement of the P&A system with this particular legal services corporation. However, there are also some disadvantages which we anticipated and at least one that we did not. The major disadvantage we saw in placement at NOLAC is the fact that NOLAC is very much identified with the New Orleans area and not with the state as a whole. Since we did not want the P&A system to share this local identity, efforts were taken to insure the system its own separate identity. Therefore, the P&A system has a separate suite of offices and its own phone number and letterhead. We continue to be concerned about the very real difficulty of serving an entire state from one office in New Orleans and look forward to a time when resources are such that branch offices can be established in other parts of the state. In the meantime, funds are being sought for a toll-free telephone number, which will enhance communication throughout the state.

A second disadvantage—this being one we did not entirely anticipate—is the potential confusion created by placing an agency within an agency. To give one illustration, NOLAC is governed by a policy making board, which is comprised of local (New Orleans) attorneys and consumers. The P&A system is guided—but not governed—by an advisory board comprised of consumers throughout the state. This situation potentially gives rise to areas of disagreement and conflict between the two boards. There is no easy way to eliminate that potential. Rather, each instance must be dealt with on an individual basis, in the hope that conflicts can be resolved through negotiation. In spite of these disadvantages, we continue to believe that in placement in a legal services corporation we have the best of both worlds—an adequate degree of autonomy for the P&A system along with the benefits inherent in being part of an established, experienced advocacy agency.

The Louisiana P&A system has three main components for carrying out the activities necessary to reach the goals of the system. Through its legal component, the system engages in legislative and litigative activities as well as in direct legal services on a limited basis. The systems advocacy component is responsible for the systems analysis of the entire state and will conduct systems investigations when called upon to do so. The information and referral component in the first year will promote the creation of at least one more citizen advocacy program in the state, in addition to delivering information and referral services.

The activities of the P&A system are carried out by a staff of five persons and are guided by a ten-member board. The P&A system maintains close contact with the Louisiana DD Planning Council and coordinates legislative and public information activities with this group. In addition, the system maintains close personal contact with other advocacy efforts in the state to insure the greatest possible impact from coordinated efforts and to avoid duplication.

The Louisiana P&A system has definite advantages in its placement, in operating under realistic goals and objectives, and in its close and personal contacts with the state DD Planning Council and other advocacy groups throughout the state. Like most other P&A systems, it has a major disadvantage in the size of its resources. Although it is still too early to make any definitive assessments, it presently appears that the advantages under which the system operates outweigh the disadvantages and that the system will be largely successful in meeting its first-year goals.

Part Three

Operation and Management

chapter 10

Management Policies for Protection and Advocacy Systems

Carolyn Knight

When the legislation mandating protection and advocacy (P&A) systems in every state was passed, Ohio had probably the largest number of already existing advocacy programs of any state in the country. The various preexisting systems in Ohio included four systems oriented to community service delivery and two systems for advocacy pertaining to institutional problems.

Since Ohio had all these preexistent advocacy systems, people thought the state had so many instant options for a P&A system that it would not need to do any planning. All it would have to do is put the pieces together to create one of the most complete systems in the country. The problem, however, was how to fit those pieces together in a way that was beneficial to everyone.

The systems had the kind of problems one might predict: poor communication, poor coordination, and almost totally adversarial relationships. Everyone agreed that the systems needed to be pulled together in some fashion, but no one could figure how to do it. No one system wanted to give up its autonomy. No system wanted to let another become the designated agency, the "boss." No one had clout to force the preexisting systems into any kind of cooperative agreements short of major legislative changes. Ohio's Section 113 money, while substantial, is not enough to fund any one of the existing systems, and worse, it cannot be matched with Title XX funds. These problems have resulted in a great deal of animosity and divisiveness within the state, which has not yet been totally resolved.

Ohio's experience with advocacy systems suggests that one problem facing the mandated P&A system, and which will only grow larger as the system develops, is the potential threat it poses to existing systems, to developmental disabilities (DD) councils, to city and state governments, and to elected politicians, such as governors. One must tread carefully, realizing that these groups and persons do not necessarily have any incentive to facilitate the success of the P&A systems. There is nothing lost in trying cooperation and communication. A good strategy is to figure out early the problems that the P&A systems will encounter in dealing with them and to approach negotiations with understanding of the different points of view involved. P&A systems have to do a great deal of homework and go that extra mile to avoid going from one adversary situation to another, which will burn them out and give their programs a reputation for big noise and little action.

In addition to working out good relationships with groups and individuals who may be threatened by the P&A system, it is important to work out ways of dealing with institutions. One of the first things the system needs to do is set up some kind of process or channel through which it has good access to institutionalized clients. Perhaps the institutional superintendent or Department of Mental Retardation and Developmental Disabilities will designate a liaison person to work with the system, or perhaps the system will have to establish its own access channels. But if it does not establish these channels, institutions can close their doors very effectively to it, especially if it begins to raise serious questions about the quality of service in institutions.

Even if things are fine in a state because personalities in different systems are meshing well, it is a mistake to become complacent or to base a system on personalities. Attempt to get cooperative agreements with other systems, spelling out specifically what is expected of them and what the P&A system will provide. Avoid waiting until a confrontation arises.

Another management problem that one has in any new program is establishing a strong, credible image. To insure the long-term existence of the whole system on a national scale, one must pick battles carefully and must win at least a few of them. It is important to the future of the P&A to have some successes, to do some things well, to build a few bridges, and make at least a few friends.

Being realistic is the key in setting priorities. There will be a great deal of pressure on the P&A system, especially at the grass roots level, from people who may expect to solve many long-standing, very knotty problems. This is neither realistic nor possible. Thus, people in charge of the P&A system have to grit their teeth and come to terms with the fact that they may not be able to solve or even deal with some of the most obvious problems, particularly in their first shaky year of existence. They may be able to take on some of these problems as the program develops and the power base grows. It will take courage to look a consumer in the eye and tell the consumer that his or her problem will not be the top priority. The P&A system will also be under pressure from some of the preexisting systems to make their problems the top priorities. Be aware of this and try to be objective in priority setting.

One big continuing battle in the P&A system exists between legal advocacy systems and all the others. Many people looked at the mandate to provide legal remedies to developmentally disabled individuals and saw no other intent in the legislation creating P&A systems. No one advocacy system is inherently superior to another. One must look at the particular needs of individual states. The most effective system is probably a blend of different advocacy programs. The legal advocacy system itself need not be limited to attorneys. The Ohio Legal Rights Service (OLRS) is using DD professionals on its staff, and this model is gaining favor all over the country. Ohio would like to contract for legal aid services by placing DD professionals within legal aid offices. This model has not, however, been implemented to date.

Successful management of P&A systems depends in part on establishing good working relationships with the people in consumer groups, institutions, other advocacy systems, and government with whom the P&A system will interact. To prevent becoming overwhelmed with demands for services and losing credibility for failure to meet the demands, the system must also be objective in setting priorities, realistic in setting goals, and firm in staying with its priorities and goals. One priority should be to build a strong image of the system by some visible accomplishments. P&A systems will minimize management problems if they spend some time at the outset of the project anticipating the needs and developing strategies for meeting the needs instead of waiting for confrontations to arise and reacting in crisis situations.

chapter 11

Potential Problems in Implementing Protection and Advocacy Systems

Robert A. Dublin

I have been asked to speak briefly concerning problems or issues which the Department of Health, Education, and Welfare (HEW) has encountered relating to the implementation of protection and advocacy (P&A) plans. The views which I express are my own and do not necessarily reflect the official opinions or policies of HEW.

HEW has encountered very few problems in the implementation of protection and advocacy plans. There are some obvious reasons for this. First, until October 1, 1977, both the department and the states, as well as outside groups and individuals, were concerned with the planning process and whether particular state plans were approvable. Second, the approved state plans have not been in operation very long. Third, problems relating to implementation surface more slowly than problems pertaining to plan approval because there is not constant, day-to-day monitoring by HEW. Nevertheless, some questions have arisen, and it is, of course, possible to think of numerous others.

Name and Citation of the Legislation

There is apparently some confusion concerning the correct popular name for the various acts which, taken as a whole, govern the protection and advocacy program. This confusion should not cause implementation problems, but it does cause misunderstanding. An illustration of this is a handwritten memorandum which I received from someone in HEW chiding me for calling this legislation, "The Developmentally Disabled Assistance and Bill of Rights Act." Unfortunately, the signature was totally illegible, so I could not respond. The correct popular name for this legislation, including public laws 91-517 and

94-103, is, "The Developmentally Disabled Assistance and Bill of Rights Act." There are three reasons for using this popular name for the series of acts governing P&A systems. First, one normally uses the most recent popular name in a series of acts for the entire series, especially since popular names are used as a kind of shorthand means of referring to a program. Second, that name appears in the official compilation which is referred to as "The United States Code" and in Section 1 of P.L. 94-103.

The correct citation to the legislation establishing the protection and advocacy requirement is Section 113 of P.L. 94-103. If you are referring to the United States Code, the correct citation is 42 U.S.C. Section 6012.

With respect to legal references, the department published notice of proposed rulemaking (or "NPRM") on August 30, 1976 for the entire program; this notice can be found at 41 *Federal Register*, pages 36582 to 36597. The final regulations were published January 27, 1977; these may be found at 42 *Federal Register*, pages 5272 to 5292. In the Code of Federal Regulations (CFR), they will appear at 45 CFR, parts 1385, 1386, and 1387.

Independence of the P&A System

One potential problem in implementing P&A systems concerns the necessity to maintain the independence of the system. This is especially important to keep in mind in those states where state planning councils serve in a formal advisory capacity, or where there is a separate advisory body other than the state planning council. To maintain this independence, those responsible for the actual operation of the protection and advocacy system must resist pressures, from whatever source they originate, aimed at stopping the system from taking actions which those who operate the system believe are necessary and proper in order to protect or advocate for the rights of persons with developmental disabilities. Responsibility for maintaining independence also rests with the state agencies and private service providers. They must not attempt to prevent the protection and advocacy system from taking actions which they may happen to oppose.

It is not improper for public or private service providers, or anyone else, to oppose views taken by the protection and advocacy system. It is legitimate to express such opposition in the legislature, in court, in the press, or in state or local government. However, it would be improper to oppose the protection and advocacy system by attempting to coerce it into refraining from taking certain actions or adopting a given policy. An example of such prohibited activity would be attempts, or threats at attempts, to remove an employee of the system unless such employee complied with demands to change a position, or drop a suit, or alter the relief being sought in behalf of a client. Of course, successful attempts to interfere in the internal operation of these systems will result in noncompliance with P.L. 94-103.

It is sometimes stated that these views sound fine, but in actuality, it is difficult for a protection and advocacy system to resist such pressures. Resisting coercion is not always easy. On the other hand, there are times when a person must take some risks in behalf of a worthwhile principle or objective. Such a risk is very much a matter of individual choice. From a more practical point of view, the first step would be to document the attempts at improper influence and then to go to others in state government, including, if necessary, the governor's office, in an effort to resist. If that strategy proves to be unavailing, the protection and advocacy system can go to interested consumer groups, or the press, or, of course, the appropriate HEW regional office.

Persons to be Served by P&A Systems

A second issue to be clarified as P&A systems are implemented concerns the definition of exactly whom the protection and advocacy system is supposed to represent. A problem in this area has arisen in a western state, so perhaps it is a question elsewhere. A position is being urged in that state that protection and advocacy systems should represent parents, not just developmentally disabled persons. Official policy is that protection and advocacy systems are to represent persons with developmental disabilities and only persons with developmental disabilities. Any other representation is improper. The statute (42 U.S.C. Section 6012) reads:

> The Secretary shall require as a condition to a State receiving an allotment . . . that the State provide the Secretary satisfactory assurances that . . . the State will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and . . . remedies to insure the authority to pursue . . . remedies to insure the rights of such persons. . . .

This legislation refers only to protecting the rights of the person with a developmental disability; it in no way is aimed at assisting parents or guardians. I personally think it very dangerous to assume that the objectives of parents, or their concerns, are necessarily synonymous with the best interests of their minor child or of their child who is a disabled adult. Thus, when a parent is seeking to have a child committed to or kept in an institution, the protection and advocacy system should look into the situation from the point of view of what is best for the person with the developmental disability. This may result in the system supporting one view or the other. Or the system might not arrive at a firm conclusion either way but, rather, would take steps to insure that the issue is resolved by a third party. In this situation, it clearly is a key role of the protection and advocacy system to insure that the third party is independent, that he or she is provided with as complete a factual record as possible, and that the law is properly applied.

Conclusion

There are undoubtedly potential implementation problems other than those I have raised. HEW is anxious for the P&A program to succeed and will gladly work with the states in clarifying the legislation and the requirements as well as advising on ways to avoid or resolve problems.

chapter 12

The Cooperative Relationship of Consumer and Professional Advocates: Principles

Ethan B. Ellis

Originally, I was asked to talk on the process of training consumer and citizen advocates. With the kind permission of the conference conveners, I have decided, instead, to focus on the cooperation between the professional and the consumer advocate in the process of advocacy.

This change in topic title has not changed the substance of what I had originally planned to talk about. The change in title is, however, important because it brings into focus the relationship which I believe should exist between the professional and the consumer advocate. Once this relationship has been mutually understood and established, the skills and abilities possessed by each can be identified and sharpened through application. Then change can occur. If this relationship is not established or understood, it will not.

A cooperative relationship between professional and consumer advocates is necessary because each has different types of skills and perspectives, and each can contribute different things to the advocacy process. Professional advocates are technicians. If their profession is law, for example, they know how laws are made and implemented; they know how courts can be used to enforce and sometimes modify them; and they understand how political and other social processes can be used to secure rights and services for the disabled. If their background is with human services delivery, they will know what financial resources and support services are available and can help with referrals.

Consumer advocates, on the other hand—disabled persons themselves and their families and friends—have the best understanding of the needs of the disabled. With the possible exception of specific medical or similar prescriptive situations, this is always true. Because of their day-to-day experience with the lives of disabled persons, they can determine when advocacy and protective services are needed. This understanding complements the technical skills of professional advocates.

The function of advocacy is to foster change—change in laws, regulations, practices, customs, or attitudes. Even the protection of individuals and their existing rights can be seen as an effort to change the practices, customs, or attitudes that threaten them. If existing rights are not protected and defended, they may be taken away; disabled persons would thereby lose one of their best tools for dealing with unfavorable customs and attitudes.

The process of advocacy requires interaction between the professional and the consumer advocate. Attorneys will recognize this as the process they engage in with their clients. That interaction can be outlined like this:

1. The consumer advocate identifies the area where change is required.
2. The professional advocate analyzes the problem and suggests alternative strategies and tactics, indicating the implications of each.
3. Together, consumer and professional advocate select a strategy and tactics and determine the role each will play or the tasks each will carry out.
4. The professional monitors the process and shares this evaluation with the consumer.
5. Each may suggest changes; both must agree to them.

It is important for the professional advocate to understand and remember that the consumer advocate must identify the problem to be addressed, must agree to the strategies selected, as well as to the role he or she will play, and must agree to, understand, and carry out any changes if they become necessary, If not, the process breaks down.

A learning process takes place within this advocacy process. The professional teaches the consumer advocate to define the change desired in operational terms, that is, in terms they can both do something about; to select strategies and tactics they understand and will be willing and able to carry out; and to understand the laws, regulations, procedures, and customs they are attempting to change, as well as their political and social implication. This knowledge helps consumer advocates grow increasingly independent and become able to do more for themselves.

I have asked my friends, Tim and Marian Doherty, to help me illustrate the principles of the cooperative relationship between consumer and professional advocates by describing a case in point (see the following chapter). The project we worked on together was exciting and fun to live through. Neither the parents' group of which they are a part nor the Public Advocate's Office could have succeeded in this project alone. Our success depended upon our cooperation.

chapter 13

The Cooperative Relationship of Consumer and Professional Advocates: Application

Tim and Marian Doherty

A group of parents in Mercer County, New Jersey, organized as "Friends of Handicapped Children," has demonstrated in the past year what consumer advocates can accomplish in cooperation with professional advocates. The parents took an institution, a private nonprofit corporation, which was performing services for the children in a halfhearted manner, and we put that place out of business. We have now a newly established special services school district for multiply handicapped children. This change was accomplished between June, 1977, when the wheels got rolling, and September 29, when the school district opened the doors to preschool and school-age children. The school is in a beautiful setting. It has a very well-qualified superintendent. It has the therapists and the professionals that we need. It is a dream and a wish come true.

We first became involved with the old center when we became parents of a handicapped child. We didn't know what the future would hold. We faced a lot of problems. So we sought help at the center, which was in southern Mercer County. When you have a handicapped child, the emotional experience of dealing with your own feelings and with your huge responsibility predominates over your thoughts about whether your child is getting a quality education. You are just coping personally with your own problems. We received services at the center until we gradually noticed certain things that were not going in the way we felt they should.

First of all, the center was housed in a very ugly building. It was condemned 20 years ago. The freeholders in the county administration felt that they were doing a favor by letting this private, nonprofit organization use the building for a nominal monthly fee. They felt that the county officials were providing what

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was needed without getting fully involved. It was just an atrocious facility. It would remind you of a monster movie. It was literally falling down. Usually two to three days a week in the winter there was no heat in this building for 60 multiply handicapped children. There were toilets freezing because it was so cold. Our children were sick constantly and no one did anything about it. But there was no other facility available to house the children.

Another problem was keeping the institution fully staffed and providing consistent therapy to the children. When a therapist would give notice that she was leaving, the administrators, instead of searching for a replacement immediately, would wait until the last day and then advertise to try to get another therapist to replace her. In the interim, half of the children would receive no therapy. The one remaining therapist would have to set priorities about whom to serve and whom not to serve. This situation certainly was not serving the interests of the children.

Another problem was that the center tried to bill the parents of school-age children for the services that the children were receiving. Under the law, the town should have paid the center for the services.

It wasn't because the parents were being billed that we started our group. What we were interested in basically was that the children have a very good program, that they get the therapy that they needed, and that they be housed in a decent facility as all the other children in the township were. The parents' group was organized to formally address these problems and to help in fund raising at the center.

After forming our parents' group, we didn't go out and contact different agencies for help. We tried to work with the administration at the center because we felt that that was the proper thing to do. We didn't want to be rabble-rousers; we didn't want to be people who criticize and tear everything down because our children weren't receiving services from this institution. We wrote letters to the board of trustees. We managed to get a parent on the board of trustees.

But after a series of efforts such as these, we found it was impossible to work through the administration. The people who were in the administration and dealing with our children were not professionals with backgrounds in special education. The board of trustees was comprised mostly of politicians, plus a few doctors. Membership on the board was honorary. The parent we placed on the board saw that there could be no improvement in our problems. He constantly brought up the building problem and found that he was just hitting a stone wall. We were desperate. We even sent a telegram to Rosalyn Carter in the hopes that by some chance she would take on our case and solve our problems.

When it became apparent that we weren't making any progress through the method of working through the administration of the center, we looked for another means of change. We sought help from professional advocates through New Jersey's Department of the Public Advocate. We had found out in trying to help ourselves that unless you have some clout, there are very few doors open to you. The Office of Advocacy helped us reach individuals who had not replied to contact from the parents' group. For example, after we had met with Ethan Ellis and the Office of Advocacy, they suggested that we call someone who could help with the financial part of our problem. We asked for an appointment without saying that the Department of the Public Advocate had suggested that we call and were told that our appointment would be from two weeks to a month from that date. When we said that Mr. Ellis from the Office of Advocacy would be very disappointed, we were told, "We'll see you tomorrow."

We have with Ethan Ellis, Herb Hinkle, and the Office of Advocacy a very close personal relationship. They have given us legal advice about the billing problem and have helped us organize our project. We actually have made all the decisions. Ethan and Herb told us what our options were and what would be the result if we made certain decisions, but we made the ultimate decision. We went to all the meetings. We contacted all the people concerned with the educational, financial, and political aspects of our problem. We did all the talking. It was the parents' group which enacted the change, with the constant guidance of the Office of Advocacy.

We don't hesitate to contact Herb or Ethan at any time or place. We really needed the strength and guidance of these two men and their office to take us through a very difficult situation and to achieve a very great accomplishment. We have now the self-confidence and the knowledge to be a little bit more independent of them. We can fight our own battles with only a little bit of guidance.

Your goal in dealing with consumers should be to give them the skills and independence that will enable them to be advocates in their own behalf. We cannot constantly run to someone to hold our hands for the rest of our lives. We have to have the skills, the strength, and the confidence to fight our own battles from here. Thanks to the support and guidance of a good Office of Advocacy, we think we will be able to do that.

chapter 14

Standards and Accreditation Procedures Related to the Protection and Advocacy Systems

Eranell McIntosh-Wilson

The words *accountability* and *monitoring* have become commonplace in the field of developmental disabilities. Since the late sixties, several instruments have been developed to assess the quality of services provided to individuals who have developmental problems. The protection and advocacy (P&A) systems, as designed and implemented at each state and local level, could adopt any one of these tools as a part of their monitoring process.

While this chapter will deal specifically with two of the standards setting agencies, there are actually four which provide standards for services for individuals who are developmentally disabled. They are the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, Joint Commission on Accreditation of Hospitals (JCAH); Program Analysis of Service Systems (PASS); Commission on Accreditation of Rehabilitation Facilities (CARF); and the federal guidelines for providing services to individuals in intermediate care facilities for the mentally retarded (ICF-MR). The two latter sets of standards are very limited in scope. CARF primarily deals with agencies which provide work-oriented programs. The federal guidelines are applicable to agencies which provide residential care for mentally retarded individuals.

PASS

The Program Analysis of Service Systems is concerned entirely with service quality in the broadest sense. It includes an optional rating instrument called FUNDET (Funding Determination), which is structured, administered, and scored in a manner analogous to the PASS, but rates only factors that bear upon whether a project should be supported financially.

The PASS scores reflect adherence to the principles of normalization as outlined by Wolfensberger (1972), other ideological service and administrative practices, administrative operations, and the process and product of service. There are 13 major elements of a service agency rated in the PASS and described below.

Physical integration (location, population, density). The service agency should be located where the majority of the individuals needing that service have immediate or at least quick access to that service. If the service agency is providing services to an entire region, then one must look at the location of that agency to insure that it is within the density of population to be served.

Social integration interpretations (name of agency, type of building). The issue is whether the name of the agency illustrates the type of services to be provided. For example, it would not be appropriate to name a sheltered workshop, "The Lollipop Center." A more appropriate name might be "Work Incorporated." The type of building is the second issue. Workshops should be provided in buildings designed similarly to those for industrial centers. In other words, a three-story house would not be an appropriate work program site.

Socially integrative program structures (deviant staff, others served). Frequently in services for individuals who are developmentally disabled, who by Wolfensberger's definition are deviant (drawing negative attention to themselves from the general community), there are several staff members or volunteers who fall into classes of individuals considered deviant. If a preschool were in need of volunteer services to provide 1:1 relationship with preschool mentally retarded children, one would hope not to find women from the local prison release programs providing these services. According to Wolfensberger (1972), having deviant staff adds to the deviancy as perceived by the community by bringing additional negative attention upon those children. Wolfensberger also contends that dealing with more than one deviant population as clients doubles or triples the negative attention that is brought to the individuals. You should not expect to find clients who are developmentally disabled, delinquents, aged, drug abusers, and alcoholics all within the same service agency.

Age-appropriate interpretations and structures (personal appearance, labels, likes, and autonomy). We frequently overlook these subtleties in monitoring services within a service agency. One revealing sign is whether the service agency takes aggressive action to assist the developmentally disabled individuals to wear hair styles and clothing that meet with the standards for their age within the general population. Another issue concerns the labels used to address clients. "The eternal child" syndrome is very clear when clients are referred to as kids, children, or boys and girls in a sheltered workshop for adults. The agency has a responsibility to assist the individuals that they serve in exercising their rights and autonomy appropriate to their age. As a monitor, we want to look, for example, at whether or not the agency is providing classes to prepare the individuals for voting, a right that is appropriate for an adult.

Culture-appropriate interpretations and structures (activities, rhythm, and routines). The issue is whether the activities provided by the agency are appropriate to the general population. For example, do individuals who are work clients sleep during the afternoon? The lunch breaks and the coffee breaks must be culturally appropriate.

Developmental growth orientation (physical overprotection). The issue here is the "right to risk" concept. Indeed, the service agency has a responsibility to insure that their clients are not put in a situation of greater risk than the general population. However, there should be adequate opportunities for the development of risk at normal levels.

Quality of setting (physical comfort, environmental beauty). We look around at the agency. Is it esthetically beautiful? Does it provide for physical comfort, including appropriate temperature, noise pollution control, and comfortable furniture? Are the clients' best interests served in terms of the quality of the setting provided in that facility?

Ideology-related administration (public education, consumer and public participation). The service agency must provide an ongoing public education program. The education program must include information regarding prevention and needs and services for individuals who are developmentally disabled. Focus on attitude change must be a part of this public information system. The issue of consumer participation is greatly overlooked. Not only are we concerned about consumer representatives such as guardians, families, and public advocates, but we are also concerned that the clients themselves be a part of that advisory group to input into the administrative philosophy and policies of that service agency.

Human science orientation (ties to academic institutions, research climate). The agency should have formal agreements with the local academic institutions to provide for staff and student exchange. Research climate refers not only to active research within the agency, but also the use of research information in providing the latest proven techniques and methods of assisting the individual served. If an agency is involved in active research, then we must look for the safeguards, human rights committees and/or informed consent boards that will indeed guarantee the protection of the rights of the clients involved.

Regional priorities (deinstitutionalization). In addition to the agency setting its own goals and objectives based on local needs, the agency must also look to a bigger picture of the regional priorities. If, for example, within the region, there is a large population of institutionalized individuals who will be returned to the community, the agency must participate in the needs assessment in order to gear up to provide the needed services.

Manpower considerations (staff development, manpower development). One of the serious problems facing agencies is locating appropriate and well-trained staff who can provide services to individuals with developmental problems. One of the ways to guarantee a cadre of individuals to provide these services is through the manpower development program of each agency. This manpower development program should be in collaboration with university programs, job corps, high school training programs—all types of training programs that will allow for a pool of individuals to be drawn upon to provide needed service at a later date. New techniques and methods of dealing with clients must be shared and explored and explained to the present staff.

Internal administration (program evaluation, planning process). In setting the goals and objectives and planning the process to meet these goals and objectives, one of the key factors to be considered is the mechanism to evaluate whether or not the agency has met its criteria. In agency planning, the goals and objectives must hinge upon the identification of the needs and goals and objectives of the population being served. The outcome of this evaluation then must be used as a monitoring device to modify the agency's long-term goals and objectives to provide needed services.

Finance (a natural item for documentation). The agency must have a mechanism for both internal and external auditing of its financial statement. As a part of the auditing of the financial statement, there must be some link between the resources, the funds, and the program to insure that those resources are being spent to meet the specified goals and objectives of the agency.

JCAH

The Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons published its first set of standards in 1971, called "Standards for Residential Facilities." This set of standards was used to survey residential facilities both large and small, private and public. Over 2,000 standards were a part of this accreditation process. In 1973, the council published "Community Agency Standards" for day programs. In 1976, the council felt very strongly that if an agency had a wide gamut of services, one set of standards would be more applicable than using separate standards in evaluating services provided by that agency. The council is publishing a set of standards applicable to all agencies, both residential and day programs, servicing the mentally retarded and other developmentally disabled persons. The JCAH standards require that each agency be a part of a network of services so as to assure that the clients receive all needed assistance in or as near as possible to their home communities, utilizing generic services whenever possible or specialized services when necessary. The standards are based on seven principles of service, described below.

Responsiveness. This principle requires that the service providers identify the needs of the population. They must survey, catalog, and utilize the resources within the system to meet those identified needs. Modifications to the goals and objectives of the service delivery system must be an ongoing process as the needs of the individuals change. Responsiveness also means the agencies within the service delivery system are responsive to individuals' appeals for assistance. Each agency may not be able to provide all the services for each applicant, but must have an identified procedure for referring to an appropriate resource which can then provide these services. There must be provisions for follow-up; otherwise, a person may not get to the appropriate services. The agencies within the service delivery system must respond to individuals who have difficulty expressing needs. There must be an active outreach program to identify individuals who are not accustomed to articulating their needs.

Availability. Service systems must make known to the general public through an affirmative action program the policies and services that they provide. There must be options and alternatives available. Service must be provided through generic resources (those used by the general public), and specialized services are developed only when there is an unmet need.

Accessibility. This can be limited by lack of information, transportation, bureaucratic red tape, fear, geographic or social isolation, language or cultural barriers, costs, or lack or responsiveness to follow-through. The service delivery system must insure that all of these barriers are put aside so that the services within that system are readily accessible to each individual in need.

Individuation. The focal point in providing services within a service delivery system is the person. The system must be an overall support system for that individual. That individual and his or her family, friends, or guardian must participate in the decision-making process to provide the services needed. Family education must be provided to assist them in the understanding and the acceptance of the individual with developmental problems. The family's role must be specified and assistance must be given to assure their part in development and implementation of the individual program plan.

Records. Records must be maintained to help a person grow. They must provide for communication among all persons and agencies involved in delivering the services to the individual. They must furnish documentary evidence of the individual's response to his or her program goals and objectives.

Quality control. Quality has to be developed, protected, and controlled. There must be a built-in mechanism within the service delivery system to monitor its operations and to bring necessary reform promptly and quickly. Quality can be measured only by comparing outcomes with goals. Goals of an agency serving developmentally disabled persons are obtained only as they help them to achieve specified objectives in their lives.

Accountability. The accreditation process is just one means by which an agency can show accountability to persons serviced and funding agencies. Surveyors' recommendations can be used to improve the program and achieve and maintain accountability status and therefore provide further evidence of accountability.

P&A systems seeking to be accredited as agencies will find the sections of JCAH standards dealing with types of advocacy most applicable. JCAH standards recognize four types of advocacy, with varying degrees of restrictiveness. Self-representation is a type of advocacy in which the individual advocates for himself or herself. The major responsibility of the agency is to train all clients to reach a point of being able to represent themselves and advocate for themselves. Personal advocacy is the next step in providing assistance to the individual. It is more restrictive than self-representation. Personal advocacy is the formal provision of friendship. Agency advocacy is a third type of advocacy. As a part of the service delivery system, there must be a formal procedure for monitoring services within that system. There must be a plan for community needs assessment, resource development, resource planning and program planning. The most restrictive level of advocacy for an individual is protective services, which are used only as a last resort in assisting an individual in meeting his or her needs. There must be a plan to move an individual quickly from this very restrictive form of advocacy back to a less restrictive form of advocacy, such as personal advocacy or self-representation.

Monitoring Technique

Figure 1 outlines the Functional Individual Program Planning process. This process, if followed, insures that individuals are receiving the needed services to meet their identified needs. This process will assist you in evaluating deficits in the service delivery system for each client and give you a guideline to assure that necessary services are being provided to meet the client's needs.

The assessment of client needs process must be provided by an interdisciplinary team of individuals who can fully evaluate the total needs of the client. Assessment should identify strengths and weaknesses in each of the developmental domains (affective, sensorimotor, social and cognitive concepts, communicative, and physical development). The interdisciplinary assessment is the base for the plan to assist each individual develop.

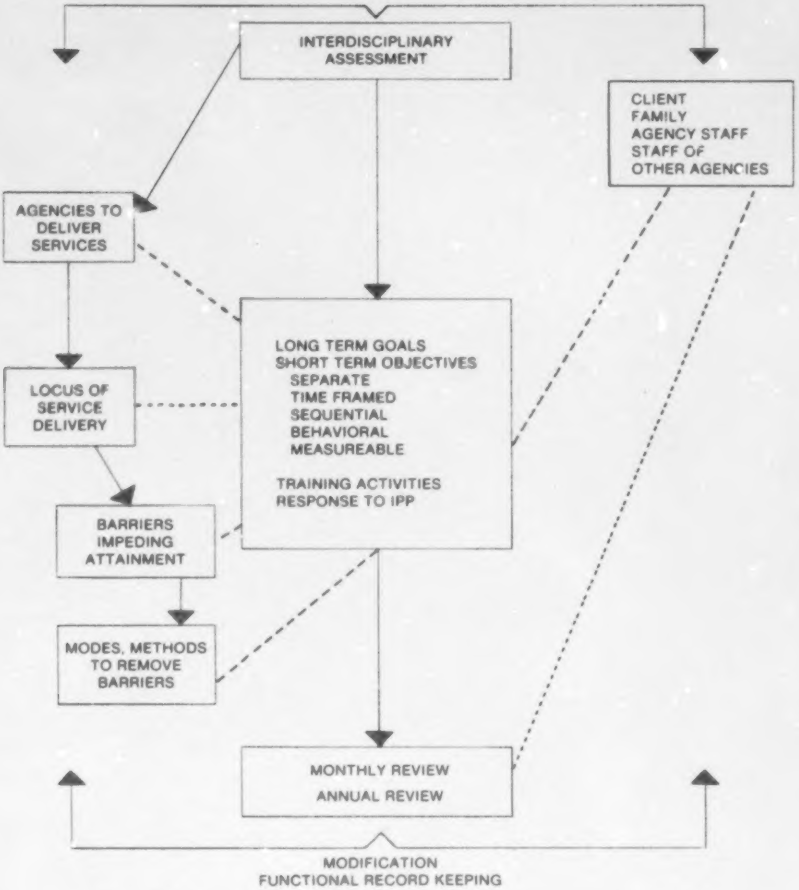
INTERDISCIPLINARY ASSESSMENT
CLIENT
FAMILY
AGENCY STAFF
STAFF OF
OTHER AGENCIES
AGENCIES TO DELIVER SERVICES
LOCUS OF SERVICE DELIVERY
BARRIERS IMPEDING ATTAINMENT
MODES, METHODS TO REMOVE BARRIERS
LONG TERM GOALS
SHORT TERM OBJECTIVES
SEPARATE
TIME FRAMED
SEQUENTIAL
BEHAVIORAL
MEASUREABLE
TRAINING ACTIVITIES
RESPONSE TO IPP
MONTHLY REVIEW
ANNUAL REVIEW
MODIFICATION
FUNCTIONAL RECORD KEEPING

Figure 1. Functional Individual Program Planning

The assessment process must identify the agencies capable of providing needed services. Each agency is not expected to have all the resources to provide all the services each client needs. Therefore, there is a need to identify which agency is best able to meet those needs. Generic services should be utilized first. Specialized services should be sought only if generic services are not available. Because an individual may be receiving services from more than one agency, the locus of responsibility within the service delivery system must be identified. There must be one agency to take responsibility to coordinate all the services provided to the individual.

The assessment process must identify barriers to meeting the attainment of the goals for the individual. The barriers may be personal barriers or systems barriers. A personal barrier, for example, may be an individual who has physical disabilities which make it very difficult for him to do fine motor tasks. Adaptive equipment within a sheltered workshop may be needed. A systems barrier may be the lack of transportation available on a regular commuter line. Adjustments would be necessary to get that individual to services needed. There must be identified methods and modes to remove the barriers. Not only do we have to identify the barriers, but also develop an active plan to remove the barriers.

The clients themselves should be involved in the process of planning for their individual programs. So frequently, an agency forgets that the clients can tell us what they want to learn, where they want to go in life, and what are the things that will help us get them there. Don't overlook them. Involve parents, guardians, advocates, or those who take on the responsibility of helping these individuals in a more formal way.

Staff members who have the expertise to assist the individual to meet his or her goals and objectives will be chosen during the interdisciplinary assessment to work closely with the individual. Staff of other agencies must be involved in providing services. Usually services are delivered by more than one agency, making it virtually impossible to plan a program without the other agency's involvement.

The plan itself has four major components: goals, objectives, activities, and response. The interdisciplinary team made up of the client, the family, and staff members of all agencies involved must assist the individual in determining his or her goals. There must be short-term objectives to assist the individual in meeting long-term goals. Short-term objectives must be separate, each having only one outcome. They must be time-framed. So frequently we set objectives for individuals with no accountability systems for either ourselves or the individual. A time frame is an estimate that can give us some guidelines as to whether or not we are moving along at a rate that will help the individual meet the long-term goals.

Short-term objectives must be sequential, that is, developmentally sequenced so that you proceed developmentally from the most basic steps to the final step to assist the individual in reaching the goal. Objectives must be written in behavioral terms that are observable and measurable. The agency has the responsibility to design training activities which assist the individual in meeting those objectives. The plan for the training activities must include the name of the trainer, the data system to be used, periods of training, and the criteria of success for each objective.

The next component of the plan is the individual's response to the activities. Response indicates how the individual is moving or not moving along the developmental continuum to reach the objectives. The responses need to be reviewed monthly by representatives of the interdisciplinary team and annually by all members concerned. The plans must be modified according to the response of the individual to training activities. If an individual is not moving progressively along the continuum, modifications must be made in training activities or the strategies to assist the individual in that movement.

Supporting this whole system is the functional record system or documentation. It must reflect the plan by which the agency is assisting the individual in meeting his or her needs. The record keeping system must provide a clear avenue of communication between members of the team. Overseeing this entire process is the individual program coordination process. While some agencies may elect to have an individual specified as an individual program coordinator, it is indeed a process, not necessarily a person. It is a process to insure that all the needs of this individual are being met, whether for living environment, programming, leisure time activities, counselling, whatever the identified needs of the individual's plan. The coordination process must assure that services are available, located, and utilized to help the individual meet his needs.

Conclusion

The two sets of standards briefly described above could be utilized in monitoring services provided to individuals who are developmentally disabled. The monitoring technique focusing on the individual (the individual program planning process) will insure that agencies meet the needs of clients. The most important factor to keep in mind in planning the monitoring services is that whatever tool is utilized, it must focus on the needs of the individual and the mechanism for meeting those needs.

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chapter 15

Evaluating Protection and Advocacy Programs

R. Lee Henney

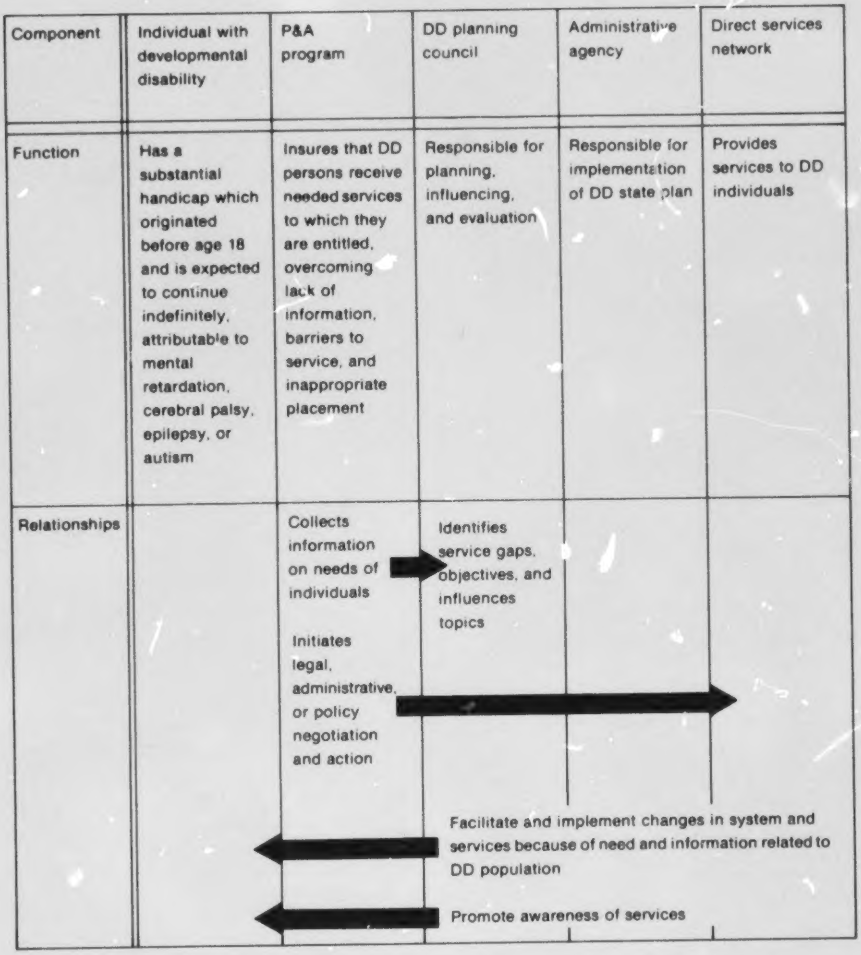
The evaluation component is one of the most important aspects of a protection and advocacy (P&A) system. Without a well-thought-out, comprehensive evaluation component, the P&A program is unable to judge its strengths and weaknesses and be responsive to the needs of the individuals who rely on the program for services. This chapter addresses five elements which should be considered when developing a comprehensive evaluation strategy:

- The P&A system in relation to the entire activity in behalf of the developmentally disabled population;
- Evaluation in relation to other essential elements of a P&A system;
- Functions served by an evaluation strategy for a P&A program;
- Items to include in the internal evaluation element;
- Items to include in the external evaluation element.

P&A and the State Program

The Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103) attempts to facilitate coordination of many different services and activities designed to benefit individuals with developmental disabilities (DD) within a state. These services and activities can be described under four categories: direct service agencies; administrative agencies; DD planning councils; P&A programs. Figure 1 displays the relationships among these four categories of services and activities.

Many state agencies and private providers make up the direct service network. State agencies such as Health, Education, and Welfare and Vocational Reha-



Component	Individual with developmental disability	P&A program	DD planning council	Administrative agency	Direct services network
Function	Has a substantial handicap which originated before age 18 and is expected to continue indefinitely, attributable to mental retardation, cerebral palsy, epilepsy, or autism	Insures that DD persons receive needed services to which they are entitled, overcoming lack of information, barriers to service, and inappropriate placement	Responsible for planning, influencing, and evaluation	Responsible for implementation of DD state plan	Provides services to DD individuals
Relationships		Collects information on needs of individuals →	Identifies service gaps, objectives, and influences topics		
		Initiates legal, administrative, or policy negotiation and action →	→	→	
		←	Facilitate and implement changes in system and services because of need and information related to DD population		
		←	Promote awareness of services		

Figure 1. Relationships among components of the DD network

bilitation play big roles in providing services. The service system varies from state to state as it provides the 16 mandated services for individuals with developmental disabilities. In some states, as many as 23 state agencies are supplying direct services to developmentally disabled persons.

In addition, each state has an administrative agency which is responsible for implementation of the DD state plan as approved by the DD planning council. The fiscal and administrative activity required by the DD planning council is also the responsibility of the administrative agency.

The DD planning council is a composite body composed of consumers, agency directors, and providers as described in Section 137 of P.L. 94-103. The council has the responsibility of supervising the development of a comprehensive state plan, which includes a statement of the needs of the developmentally disabled population, a description of the service network, and an identification of the gaps in the service network. The state plan also includes a description of the operation of the council, its objectives, and the budget for the year. Moreover, the DD planning council is responsible for influencing legislation to benefit the population and for evaluating programs provided for developmentally disabled individuals.

The newest state DD program is the P&A program, implemented as of October 1, 1977. The P&A program uses policy and administrative and legal procedures in individual case negotiations to insure that individuals with developmental disabilities receive needed services to which they are entitled. There are three identifiable categories of reasons why individuals do not receive needed services; the P&A program provides representation for individuals in each of these situations and contains program elements which address each situation. First, a lack of knowledge exists. Many individuals in need of service do not know what services are provided or to which services they are entitled. Second, program barriers—which have their origin in policy decision, administrative regulations, and legal prohibitions—prevent individuals from receiving needed services. Third, inappropriate placement hinders some individuals from receiving services which are appropriate for their condition or need.

Essential Elements of a P&A Program

Nine elements are essential to a P&A program and have been outlined in many of the approved state P&A plans. These nine elements are: public awareness, training on five levels, materials development, individual case negotiations, individual case referral, follow along, permanent financial base, utilization of information, and monitoring and evaluation.

Each element is a professional discipline within itself. Minimum allotment states in particular are hard pressed to produce the comprehensive program which is contained in many approved plans unless a great deal of coordination of resources already exists within the state.

Public awareness. The P&A program must be announced statewide, visible, and available statewide. This requirement was established in the *Guidelines* issued by the Developmental Disabilities Office (DDO, 1976) Washington, DC. These activities require the knowledge of how to reach the population within the state, how to describe the target population, and how to keep the public aware of services available.

Training. The DDO *Guidelines* require each state plan to contain a training element. Five populations can be included in P&A training: staff; general public; consumers; citizen advocates; and professionals. Each population requires a different training strategy and technique. Staff training involves an introduction to the disabled population and the highly complex service system. Training of the general public is difficult because of misunderstanding, apathy, and general lack of interest in disabled persons. Consumers need to be trained as self-advocates, and volunteers need instruction in citizen advocacy. The training of professionals may focus on providing an understanding of the needs of the target population, diagnostic procedures, and/or services which exist.

Materials development. Most programs propose to have information packets on two subjects. First, they intend to develop materials on the rights of individuals with developmental disabilities. And second, they propose to provide information on the services available for individuals with developmental disabilities

Individual case negotiation. This activity is the core of the entire P&A effort. It requires that the advocate know the service network, funding streams, and rights of individual clients. It also requires that the advocate be able to solve the problem at the lowest level of jurisdiction. Negotiation can take the form of either policy, administrative, or legal redress by the P&A program. Sharing sample case histories and precedent case histories will be extremely valuable to advocates.

Individual case referral. The objective of a P&A project is to match disabled persons with appropriate needed services to which they are entitled. In order to achieve this objective, the P&A system will need a responsive, well developed information and referral service, including specific qualification requirements for program acceptance at the local level. Sharing procedures for establishing information and referral programs will be economically significant and valuable to the P&A programs throughout the country.

Follow along. This activity is one of the 16 mandated services in P.L. 94-103 (Section 133) and is extremely important in a P&A program. Follow along is individual case management which insures that an individual with developmental disabilities is receiving the continuum of services at the time of critical need. The reason people need the services of a P&A program is that they are not in the service system or need additional services. Usually these people have "fallen through the cracks" of the service delivery system. A P&A program must not allow them to continue to fall through the cracks once they have become clients of the P&A program.

Development of a permanent financial base. This activity is important to insure the continuation of the P&A program. Especially in minimum allotment states, there is a need to expand the funding base for the program. Too many times society has started programs for individuals, only to let them die for lack of adequate funding. The P&A program, because it serves a very vulnerable population, must not suffer this fiscal inadequacy. A permanent and adequate funding base must be obtained in the first year.

Utilization of information. A P&A program by its very nature will generate a great deal of information about topics such as barriers to services, problems in accessing the system, and complaints about the service system. This information should be carefully analyzed and distributed to interested organizations and individuals, since sharing information will be significantly helpful to P&A coordinators and programs.

Monitoring and evaluation. Attachment 3.2 of the DDO *Guidelines for Protection and Advocacy Programs* requires each state to include a description of internal and external evaluation strategies in its P&A plan. Internal and external evaluation will be discussed in more detail below. Also, the P&A program needs a built-in process of monitoring local direct service programs in order to be able to refer clients to reliable programs. Sharing evalution and monitoring methodologies among P&A programs will be of value to the P&A systems nationally.

Functions of an Evaluation Process

The evaluation strategy should be a nonacademic, comprehensive, ongoing assessment mechanism which serves the following nine functions: It benefits the entire system, reports the flexibility of the program, assesses the program in relation to environment, is a part of the total P&A program, includes all key program ingredients, contains quantitative and qualitative information, provides feedback, documents the process, and documents the outcomes.

It is important that the evaluation process benefit the entire DD system, including the service system, the administrative agency, the deliberations and actions of the DD planning council, and the internal workings of the P&A program. The ultimate goal of the evaluation process should be to benefit individuals with developmental disabilities. To achieve this goal, the P&A program must be responsive to the real world needs of the clientele. Particularly in this first year of implementation, the activities of the system must be flexible. The evaluation of the system should report the ability of the P&A system to be responsive to the revealed needs of the clientele during the program operation. Moreover, the evaluation program should assess the program in relationship to the environment in which the system functions. The program, its process, and its actions must be compatible with the environment in order to produce the most cost-effective services for individuals with disabilities.

The evaluation process must be continuous and a part of the total P&A program cycle, which includes planning, implementation, evaluation, and planning. The evaluation process is the integral part upon which planning is based, linking the program activity with the direct needs of the clients. The key program ingredients should be part of the evaluation process. In addition to the essential elements of a P&A program already reviewed, these key ingredients include the program process, staff, resources, and the organization and management of the program.

Quantitative and qualitative information and feedback should be produced by the evaluation process. The quantitative information should include number of cases, type of cases, type of services, and disposition of cases, while the qualitative information should include attitudes of clients, case loads for advocates, and narrative descriptions concerning relationships with other organizations. Feedback should be provided to all interested parties. The internal evaluation must provide feedback to staff, council, service agencies, and clients, and the external evaluation must provide feedback to the program administration, federal and state officials, and clients.

Finally, the evaluation also should report the process and outcomes of the P&A program. The external evaluation component should focus on the process used to implement the P&A program. The DD planning council has the legislative mandate and perspective to perform this evaluation. The elements of the external evaluation will be discussed below. Reporting outcomes is a specific goal of the internal evaluation component of the program as required in Attachment 3.2 of the DDO *Guidelines*. These measurable outcomes will be discussed in detail in the next section of this chapter.

Internal Evaluation

Each state must, according to the DDO *Guidelines*, describe its internal evaluation strategy in its P&A plan, and report periodically on the implementation and effectiveness of the strategy. Many states are required in their approved P&A

plans to make a monthly internal evaluation report. Such reports should contain four types of information: quantitative information displaying program outcomes, qualitative information describing achievement of plan year objectives, narrative describing necessary program changes, and fiscal information compared to proposed budget items.

Because it provides direct services to individuals, the P&A program can be evaluated according to program outcomes. These outcomes can be presented through quantitative data on clients, services, and referrals. Although the specific information to be reported will vary somewhat from state to state, in general it should include the number of clients requesting service, the number of clients provided service, and the number of clients presently receiving service. Additional useful data would include the number of service cases closed, the type of services provided, the number of referrals made and agencies used for referral, and the number of clients rejected for service and reasons for rejection.

Second, the internal evaluation report should contain information describing the progress toward meeting plan year objectives. In Attachment 2.2 of the DDO *Guidelines*, each state is required to write measurable plan year objectives. This part of the report also may include qualitative information describing the effectiveness of the program. One method of securing this type of information is to encourage feedback from clients through the use of client evaluation forms or interviews. One state, for example, intends to take a random sample of clients and use direct interviews to gather information regarding the quality of program operations. In addition, this section of the report can contain a description of staff activity as it relates to providing services and meeting plan year objectives. The report also might describe how the program insures that the rights of disabled persons are protected through program activities.

The third part of the internal evaluation report should describe how the program procedures and activities have been changed to meet the needs of the real world. The P&A program will require modification if it remains responsive to client needs and to the environment. The plan is a statement from which to start. Responsiveness to actual situations is the genius of any social program. However, documentation should be made when the responsive action requires modification of the plan in order to maintain continuity in the planning cycle. Many times, the reasons for program modification provide clues to barriers and needed action in the service network to provide more and better services to our clientele.

The final part of any internal evaluation report should be a fiscal report, using the proposed budget as the base document. This part of the report should include a description of the progress being made in securing permanent funding for the P&A program in the state.

External Evaluation

The DDO *Guidelines* require that each P&A program be evaluated annually by an outside (external to the program) agency. The approved P&A plans in many states indicate that the DD planning council will perform this function for many programs. Other programs plan to use university affiliated programs or other organizations to perform the external evaluation.

The contents of the external evaluation report, as described in Attachment 3.2 of the DDO *Guidelines*, should be primarily concerned with program process rather than program outcomes. Program outcomes will be documented through the internal evaluation report described above. Evaluation of program process is concerned with how services are provided to the individuals. An external evaluation should address the following questions about the P&A program:

> Is it effective in reaching the DD population throughout the state? Is it visible? Is it known?
>
> Is it effective in coordinating the efforts of all advocacy programs within the state?
>
> Is it effective in reaching its plan year goals and objectives?
>
> Is it effective in conducting training programs for staff, consumers, citizen advocates, the general public, and professionals?
>
> Is it effective in working with significant DD groups such as service providers and the DD planning council?
>
> Is it effective in creating and distributing materials which describe the rights of the disabled as well as the availability of services?
>
> Is it effective in protecting the rights of individuals with developmental disabilities?
>
> Is it effective in securing an adequate and permanent funding base for the P&A program?
>
> Is it effective in understanding and interpreting the needs of the real world?

The external evaluation should be conducted in accordance with the stated objectives in the P&A plan and should be specific to that plan and program. The primary benefit of the external evaluation process is to provide the P&A program with another perspective of itself for the purpose of delivering the best services possible to the individuals in need. The external evaluation process should include a feedback component which permits the P&A program to use the information for program improvement and modification.

Summary

P.L. 94-103 requires that many different services, programs, and activities be coordinated in an effort to provide a continuum of services for individuals who most likely will need a lifetime of services. Every individual, agency, and organization in the DD service network is working toward the same goal: to provide appropriate services to individuals with developmental disabilities at their time of need.

The P&A program provides an individual with a link to a complex service system which can be confusing and overpowering. Barriers to services often exist because hard questions such as "Why not?" and "What does it take to change it?" are not asked. The P&A system must continually ask the hard questions. The evaluation process must insure that the correct hard questions are being asked for the benefit of individuals with developmental disabilities. Evaluation must be ongoing and client oriented. The evaluation process must not only document the outcomes of the P&A program but also provide a road map to guide the delivery of comprehensive services in a timely manner to disabled individuals. The P&A system must not allow individuals to fall through cracks in the service system. In addition to a self-check by the P&A program, an objective, third-party check also is needed. to insure maximum productivity and benefit.

The P&A program presents our population with a practical, understandable program wherein their needs are analyzed and met. In a society that often is mechanical in the delivery of social services, the P&A program is based on the dignity of individuals caring for the needs of individuals. We are off to a good start, and with the dedication exhibited by the people involved in the P&A program, this program promises to have a significant impact for individuals with developmental disabilities throughout the country.

Reference

Developmental Disabilities Office, Department of Health, Education, and Welfare. *Interim guidelines for development and implementation of a system for protection of the individual rights of and advocacy for persons with developmental disabilities.* Washington, DC: Author, November 1976.

chapter 16

Unnatural Resources

Paula Breen Hammer

Recently, one of America's most incisive social commentators, Lily Tomlin, focused attention on the "crisis of unnatural resources" (1977). In the persona of Judith Beasley, who is "not a professional actress, but a real person like yourself," Tomlin gives some good consumer advice:

> Most of us are aware of our diminishing supply of natural resources, but did you know we are also running short on unnatural resources? Until recently I, like so many of you, thought there was enough plastic in the world to go around. Apparently, this is not true. You hear all this talk about saving trees. Well, trees can be grown; with plastics you have to start from scratch.

Protection and advocacy (P&A) systems can surely identify with the problem of having to start from scratch. The terms *unnatural resources* and *genuine synthetic crisis* could easily be used to describe the fiscal, information, and manpower shortages facing P&A systems.

The topic of this presentation is the distinctly "unnatural" realm of resources which may be available to support the work of P&A systems in behalf of individuals with developmental disabilities. What is unnatural is the complex and often interlocking array of public law numbers, title and section numbers, regulations, procedural guidelines, matching rates, income eligibility rules, appropriations levels, federal-state-local/public-private interconnections, and so forth. The jargon may seem unnatural and deadly, but the information is essential to any effort to fully implement advocacy and protective services for developmentally disabled (DD) persons.

This paper, updating an earlier article (Hammer, 1977), focuses on federal level resources for P&A systems and outlines basic information sources for tracking down both public and private funding sources. It reviews three categories of public sector support:

Prime targets (very likely funding sources), such as Title XX Social Services, Title XX Open End Training Funds, and the Legal Services Corporation;

Block grant programs, such as the Comprehensive Employment and Training Act (CETA), Housing and Community Development Act, and General Revenue Sharing;

New entitlements for certain disabled children under Supplemental Security Income (SSI) Child Referral for Services.

PRIME TARGETS

Title XX: The Service Program

The Social Security Amendments of 1974 (Public Law 93-647) consolidate the federal-state social services programs in a new Title XX of the Social Security Act. Title XX became effective October 1, 1975, and replaced social services provisions found in Titles I, IVa, VI, X, XIV, and XVI (except for Puerto Rico, Virgin Islands, and trust territories).

Provisions of Title XX offer states new opportunities to develop programs, including advocacy and protective services for developmentally disabled persons. The law significantly broadens eligibility criteria to include, at a state's option, families with income up to 115% of the state's median income (nationwide, approximately $15,800 for a family of four). Income levels may be different in different services. And in fact, as Table 1 shows, seven states apply more generous income eligibility criteria to developmentally disabled persons than to others. All 50 states make services available to DD persons who are income maintenance recipients.

Developmentally disabled residents in community based sheltered living arrangements, including group homes, apartments, and hostels, are eligible to receive a variety of services funded by Title XX. Social service funds may also be used for an individual in public or private institutions (including skilled nursing facilities and intermediate care facilities) as part of the plan for that individual to return to the community. These so-called "in reach" services must be provided by an agency outside the institution. In addition, eligibility for Title XX services may now be permitted on a group basis so long as 75% of those served have incomes at or below 90% of the state's median income (Social Legislation Information Service, 1977). Group determinations may not, however, be made for child day care services except for children of migrant workers. Provisions to allow eligibility determination on a group basis were enacted in September, 1976, amendments to P.L. 94-401 (Morris Associates, 1976).

TABLE 1

CASP[a] Data on Cut-off Point for Title XX Eligibility Expressed as Percent of Median Income (Adjusted)

State	Developmentally Disabled Persons	Other Persons
Colorado	80%	55%[d]
Hawaii	79%	60%
New Mexico	115%	80%
Ohio	80%[b]	54%
Tennessee	80/115%[c]	70%
Utah	115%	80%
Virginia	70%	50%

Note. From "Technical Notes: Summaries and Characteristics of States' Title XX Social Services Plans for Fiscal Year 1977" by E. Wolff, B. Bind, and P. Sullivan, Department of Health, Education, and Welfare, March 1977, 14-28.

[a] Comprehensive Annual Services Program Plan.

[b] Ohio provides most services to 80% if an individual is mentally retarded or mentally ill.

[c] Services to physically or mentally disabled persons are available to 80%. Day care for a physically or mentally disabled child under age 4 is available to 115%.

[d] Includes AFDC/SSI/EP recipients for all services. Day care services are available to 55% under certain conditons.

What services may be funded under Title XX? States must provide four universal services to everyone without regard to income: protective services for children, protective services for adults, information and referral, and family planning. States have considerable latitude to define any other services to be offered under Title XX so long as the services are directed at one of the five goals set forth in Title XX. These goals include achieving or maintaining self-sufficiency, including reduction or prevention of dependency; preventing or reducing inappropriate institutional care by providing for community based care, home based care, or other forms of less intensive care; and screening, referral, or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions. All services have a 75/25% federal match except family planning, which is 90/10%.

How are states spending their Title XX funds? Analysis of Comprehensive Annual Services Program Plans (CASPs), which are filed to show how states plan to use Title XX funds, indicates that day care receives the largest single proportion of Title XX funds (24.1%). Table 2 shows relative expenditures for basic service categories for both fiscal years (FY) 76 and 77. Comparison indicates a slight relative increase for child protective services, but relative decreases for adult protective services and legal services.

TABLE 2

Changes in Estimated Title XX Expenditures: FY 76 - Fy 77

	Percentage of Total Budget[a]	
	FY 76	FY 77
Home based services	11.5	13.2
Protective services—child	7.2	8.1
Substitute care—child	8.8	8.2
Home/congregate meals	1.06	1.2
Adoption	1.2	1.1
Legal Services	1.5	1.4
Services to unmarried parents	.7	.6
Protective services—adult	2.1	1.6
Housing services	1.1	.9
Information and referral	3.9	3.6
Adult day care	1.7	1.4
Transportation	2.3	2.0
Family planning services	2.8	2.2
Child day care	25.2	24.1
Health and mental health services	5.2	4.4

Note. From "Technical Notes: Summaries and Characteristics of States' Title XX Social Services Plans for Fiscal Year 1977" by E. Wolff, B. Bind, and P. Sullivan, Department of Health, Education, and Welfare, March 1977, vi.

[a] Not all state service data are captured in this table. Only certain services are selected by HEW for interstate reporting. Therefore, columns do not add up to 100%.

Legal services under Title XX. As defined in the FY 77 final CASP plans, legal services are non-criminal, non-fee-generating legal matters. Typical problems met by this service include child support, divorce, adoption, housing, civil rights, employment, guardianship, and commitment to institutions. In FY 77, $33.3 million in federal social service money was spent for legal services. Legal services comprised 1.4% of total Title XX social service expenditures and reached an estimated 366,746 people. Thirty-three state plans specifically define legal services for Title XX funding. Eighteen states do not list legal services in the CASP. (However, many of these states offer legal services as a component of their protective services.) Twelve states plan to provide legal services without regard to income when the service is directed toward preventing or remedying neglect, abuse, or exploitation of children and vulnerable adults. These states are Alabama, Colorado, Iowa, Maine, Maryland, Missouri, New Mexico, Ohio, South Carolina, Tennessee, Virginia (court services only), Wisconsin, and Wyoming. Table 3 displays FY 77 expenditures by state for legal services.

How much money may be available in my state? Federal allocations for Title XX have been limited to a $2.5 billion ceiling nationally. Each state is eligible to match up to a maximum state allotment. Table 4 lists FY 76 utilization for Title XX in each state. Seventeen states spent all of their allotment and nine other states are at 90% of available funds. The Department of Health, Education, and Welfare (HEW) estimates that 33-35 states will spend their entire allotment for FY 77, and 5-7 states will reach or exceed the 90% mark (see Table 4).

If a state is spending at or close to its ceiling level of funding, then the probability of a new Title XX service grant or contract is very low. For these states, the word is, "Don't despair." Even though the state is using all available service money, two avenues to Title XX remain open: Title XX training funds, which come from a separate unlimited authorization; and the likely possibility of increased federal allotments in the near future. These two sources will be described below. If, however, your state is significantly *underspending* on Title XX, it is open season to match and access Title XX funds for component services of the P&A system.

P&A personnel in states that appear to have excess, unused Title XX service dollars should consider the following basic tasks essential to accessing Title XX funds:

- Identify the designated Title XX agency in the state, usually a state welfare, social service, or human resource department.
- Identify and establish communication with Title XX agency staff.
- Obtain a copy of the state plan for Title XX; analyze the plan and make written comments to the agency.
- Become familiar with federal regulations governing Title XX.
- Work with the state Title XX agency to get advocacy and protective services included in the state plan, by amendment, if necessary.
- Identify sources of state-local match including:
  - Federal general revenue sharing funds allocated to state and local governments which may be used to match federal Title XX funds;
  - Local public funds, municipal, or county general revenue;
  - State public funds (state legislature appropriations including budgets for state agencies such as mental health, mental retardation, aging, transportation, youth services, corrections);
  - Private, nonprofit, donated funds (foundations, voluntary agencies, United Way, church groups, etc.).

Examples of some independent legal services programs receiving Title XX funds are the Montana Legal Services Association, which receives $240,000 from Title XX and provides statewide services; the Colorado Coalition of Legal Services Programs, which receives $700,000 in Title XX money; the Pennsylvania Legal Service Center; and the Virginia Legal Services Corporation.

TABLE 3

Title XX Funds for Legal Services in FY 77 by State

	Legal Services Estimated # of Clients FY 77	Legal Services Estimated Expenditures FY 77	Title XX Final Plan Budgets FY 77	Legal Services % of Total Title XX Budget FY 77
Alabama	12,000	$ 1,443,732	$ 56,219,896	2.6
Alaska	a			
Arizona	4,008	367,363	32,411,119	1.1
Arkansas	a			
California	3,289	351,245	407,395,431	.09
Colorado	4,583	1,233,873	39,191,700	3.2
Connecticut	19,102	1,918,103	58,608,241	3.3
Delaware	700	66,666	9,021,498	.7
District of Columbia	a			
Florida	4,869	438,498	125,625,549	.4
Georgia	4,200	693,158	79,633,239	.9
Hawaii	a			
Idaho	a			
Illinois	571	28,571	188,662,743	.02
Indiana	50,457	614,286	40,796,661	1.5
Iowa	1,973	50,659	45,627,645	.1
Kansas	1,250	109,692	35,678,095	.3
Kentucky	a			
Louisiana	a			
Maine	400	164,771	16,220,833	1.0
Maryland	12,874	1,555,958	64,505,690	2.4
Massachusetts	800	600,000	117,031,336	.5
Michigan	a			
Minnesota	4,192	552,380	61,720,224	9
Mississippi	a			
Missouri	53,692	2,024,788	75,442,978	2.[illegible]
Montana	2,400	200,000	11,270,000	1.8

TABLE 4

Actual Use of Title XX Social Services Funds in FY 76 by State

	Total Use of Federal Allotment FY 76	Federal Allotment FY 76	% of Allotment Spent FY 76[a]
Alabama	$ 29,900,310	$ 42,250,000	71
Alaska	4,000,000	4,000,000	100
Arizona	6,434,197	24,500,000	26
Arkansas	11,948,505	24,250,000	49
California	245,500,000	245,500,000	100
Colorado	28,999,965	29,000,000	100
Connecticut	36,750,000	36,750,000	100
Delaware	6,365,550	6,750,000	94
District of Columbia	9,000,000	9,000,000	100
Florida	89,045,043	91,500,000	97
Georgia	52,270,283	57,000,000	92
Hawaii	8,322,329	10,000,000	83
Idaho	9,250,000	9,250,000	100
Illinois	94,127,339	133,750,000	70
Indiana	8,707,974	63,250,000	14
Iowa	34,500,000	34,500,000	100
Kansas	17,613,254	27,250,000	65
Kentucky	39,750,000	39,750,000	100
Louisiana	31,839,730	44,750,000	71
Maine	10,100,510	12,250,000	83
Maryland	43,972,900	48,500,000	91
Massachusetts	64,108,618	69,250,000	93
Michigan	102,837,187	107,750,000	95
Minnesota	46,498,929	46,500,000	100
Mississippi	8,321,227	27,250,000	31
Missouri	28,230,178	56,750,000	50
Montana	8,500,000	8,500,000	100

Nebraska	a				18,250,000	18,250,000	100
Nevada	a				3,824,090	6,500,000	59
New Hampshire	419	104,943	12,605,948	.8	7,159,145	9,500,000	75
New Jersey	21,118	2,545,854	115,019,825	2.2	82,480,142	87,750,000	94
New Mexico	651	173,699	17,298,160	1.0	10,614,823	13,250,000	80
New York	a				217,500,000	217,500,000	100
North Carolina	7,500	1,497,360	82,362,493	1.8	41,356,243	62,750,000	66
North Dakota	10	9,452	10,000,000	.1	5,518,110	7,500,000	74
Ohio	21,498	1,757,909	169,397,133	1.0	61,471,744	127,750,000	48
Oklahoma	a				26,605,714	31,750,000	84
Oregon	a				25,464,676	26,500,000	96
Pennsylvania	82,000	10,915,365	206,691,100	5.3	115,402,679	141,750,000	81
Rhode Island	a				11,500,000	11,500,000	100
South Carolina	2,804	333,505	43,544,277	.8	27,683,910	32,500,000	85
South Dakota	a				6,552,320	8,250,000	79
Tennessee	9,177	474,386	56,253,038	.8	28,335,546	49,250,000	58
Texas	a				140,500,000	140,500,000	100
Utah	1,360	177,594	18,500,100	1.0	10,334,625	13,750,000	75
Vermont	3,097	180,500	7,919,319	2.3	5,500,000	5,500,000	100
Virginia	13,409	1,650,738	78,724,459	2.1	38,181,073	57,250,000	67
Washington	a				40,749,990	40,750,000	100
West Virginia	639 (Monthly)	400,000	28,907,521	1.4	19,540,299	21,500,000	91
Wisconsin	21,657	570,286	77,730,000	.7	54,500,000	54,500,000	100
Wyoming	686	100,093	5,588,105	1.8	3,769,353	4,250,000	89
TOTAL	366,746[b]	33,305,427	2,395,614,256	1.4	2,079,688,510	2,500,000,000	83.2

Note. From "Technical Notes: Summaries and Characteristics of States' Title XX Social Service Plans for Fiscal Year 1977" by E. Wolff, B. Bind, and P. Sullivan, Department of Health, Education, and Welfare, March 1977, 188.

[a] Eighteen states do not include legal services in their social service plans; most of these states describe legal services as necessary components of other services, e.g., Protective Services, Substitute Payee, Adoption.

[b] Estimated number of persons served excludes the monthly population estimate in West Virginia.

Note. From "Technical Notes: Summaries and Characteristics of States' Title XX Social Service Plans for Fiscal Year 1977" by E. Wolff, B. Bind, and P. Sullivan, Department of Health, Education and Welfare, March 1977, 6.

[a] Percentages have been rounded.

P&A systems should be alerted to possible conflicts that may arise when funding agencies (e.g., state welfare departments) require legal services to report information about clients which may be viewed as protected by lawyer-client confidentiality. The Illinois State Bar Association Professional Ethics Committee, for instance, has issued an opinion on such requirements that attorneys and legal services organizations should not honor these requests without informed consent (National Clearinghouse, 1977). For information on use of Title XX for Legal Services contact:

National Legal Aid Defender Association
2100 M Street, NW
Suite 601
Washington, DC 20037
202/452-6020

INFORMATION SOURCES TITLE XX SERVICE PROGRAM

P.L. 92-647—the 1974 Amendments to the Social Security Act establishing Title XX;

P.L. 94-401—recent amendments;

Federal Register—Regulations 1/31/77, 12/2/77;

Your state's CASP plan;

State departments of public welfare;

Regional Office of HEW, Office of Human Development Services.

INTERPRETIVE MATERIALS AVAILABLE TITLE XX SERVICE PROGRAM

Child Advocates' Checklist for Review and Summary of State Title XX CASP Plan
Hecht Institute for State Child Welfare Planning
1346 Connecticut Avenue, NW
Washington, DC 20036

Breaking Through the Maze: Title XX of the Social Security Act
Grantsmanship Center News
1015 West Olympic Boulevard
Los Angeles, CA 90015

Finding, Obtaining, and Audit-Proof Contracting for Federal Money for Children
Manuals 1, 2, 3
Hecht Institute for State Child Welfare Planning
1346 Connecticut Avenue, NW
Washington, DC 20036

Analysis and Strategies for Child Advocates on P.L. 94-401
Day Care and Child Development Council of America
1012 14th Street, NW
Washington, DC 20005

Title XX: Training Funds

Title XX Training Funds are available to the designated state agency for Title XX at 75/25% federal/state-local share, that is, $3 in federal funds for every $1 in state-local funds. The state agency may use the funds to pay for training:

Current personnel and volunteers of the state Title XX agency (e.g., Department of Public Welfare);

Current personnel and volunteers of a provider agency receiving Title XX funds (e.g., nonprofit organization under grant or purchase of service contract with Title XX funds);

Persons preparing for employment in the Title XX agency.

The state agency may dispense these funds to individual students, to educational institutions, and to public and private providers of services, such as P&A systems. In FY 76, federal expenditures under Title XX training amounted to almost $18 million. States not-at-ceiling in the regular service allocation can use funds from the regular service allotment for training. Those states spending at or above their ceiling for Title XX services may tap an open-ended authorization for training funds. In the past, these funds have been used largely for educational leave for state employees, especially social workers in degree programs. Funds may, however, be used for short-term training and in-service training. Last year, 65,200 individuals attended workshops and seminars funded by Title XX training money.

The P&A system could access Title XX funds on a grant, a contract, or third-party reimbursement basis from the state Title XX agency for the following types of expenditures:

Training of citizen advocates, paralegals, day care providers, parents, foster parents, group home personnel—both paid staff and volunteers;

In-service training for staff and volunteers of the P&A system;

Salary of a full-time staff development person;

Costs of curriculum development, instructors' salaries and fringe benefits, instructional material, equipment, clerical assistance, and classroom overhead costs.

For those states currently utilizing all available Title XX services, funds relief may be on the way in the form of legislative proposals to raise the Title XX ceiling to $2.9 billion (the Fraser-Keys bill, HR 11237). In fact, in 1977 and 1978 an additional $200 million in 100% federal funds, earmarked for day care programs, was allocated to Title XX programs. The administration's budget for 1979 proposes to retain the $200 million in day care funds. If, in fact, the ceiling level set in 1972 is increased, P&A systems should be prepared to submit program funding requests to the state Title XX agency.

INFORMATION SOURCES: TITLE XX TRAINING FUNDS

Federal Register, 8/26/76, proposed regulations for Title XX [45 CFR, Part 228] Section H "Training and Retraining"

State Title XX agency

State Management and Training Staff
Office of Human Development Services
Department of Health, Education, and Welfare
330 C Street, SW
Washington, DC 20201
202/245-1724

INFORMATION ON TRAINING AND UTILIZATION OF PARALEGALS

The National Para-Legal Institute
200 P Street, NW, Suite 600
Washington, DC 20036
202/872-0655
Nancy Kleeman or Patricia Powell

Materials available include:

Teaching Advocacy: Learner-Focused Training for Para-Legals ($5.00)

Legal Interviewing for Para-Legals ($3.00)

Introduction of Civil and Criminal Litigation Roles for the Para-Legals ($3.00)

Basic Substantive Law for Para-Legals: Contracts, Torts, and Due Process ($3.00)

Supplemental Security Income: An Advocate's Handbook ($6.00)

Legislative Analysis: How to Use Statutes and Regulations ($7.50)

Legal Services Corporation

The federally authorized Legal Services Corporation (LSC) was created in 1974 to continue the legal aid programs initiated under the Office of Economic Opportunity (OEO) in the sixties. In FY 76, the Legal Services Corporation spent $96 million nationally to support general legal aid programs for low income individuals. Public Law 94-222, enacted December 28, 1977, extends the Legal Services Corporation Act through September 30, 1980.

The corporation provides funds to approximately 300 legal services programs reaching clients through 700 offices in all 50 states and the territories. Eligibility standards are tailored by each program, but maximum annual income levels for clients is set at 125% of the poverty level (currently $3,713 for an individual; $7,313 for a family of four). The 1977 legislation highlighted the handicapped and elderly as groups to be given special priority.

The Legal Services Corporation is now authorized to fund a small number (not to exceed 10% of its annual appropriation) of contracts and grants to provide research, training, technical assistance, and clearinghouse information activities. Among the discretionary project grants identified for priority funding in FY 78 were innovative demonstration programs to educate clients about rights, self-advocacy, and initiatives to make legal services accessible to handicapped persons. P&A systems for disabled persons might explore the possibility of buying into existing legal aid programs, sharing support services, space, law libraries, and other cooperative efforts.

An excellent back-up center, formerly funded through LSC, is the National Senior Citizens' Law Center in Los Angeles. The center, though concentrating on problems of elderly persons, has generic expertise in problems related to handicapped persons, especially Supplemental Security Income, Social Security, administrative appeals, Medicaid, Privacy Act, and Freedom of Information. The center is staffed by skilled advocates who have been in the business for some time and could provide valuable assistance to new advocacy programs for developmentally disabled persons.

In addition, Legal Services Corporation supports a number of back-up centers to provide technical assistance, materials, and training for legal services programs. A list of the LSC back-up centers appears in Table 5. P&A systems should explore the manpower and information resources of these groups that can be accessed through local legal services programs and, in many cases, directly.

INFORMATION SOURCES: LEGAL SERVICES CORPORATION

Legal Services Corporation
Room 413
1725 K Street, NW
Washington, DC 20006
202/245-6325

Federal regulations in the *Federal Register*, 9/12/75

National Senior Citizens' Law Center
1709 W. 8th Street
Los Angeles, CA 90017
213/483-3990

BLOCK GRANTS

Units of general purpose government (states, counties, towns) are now receiving massive amounts of federal funding under three block grant programs. These include general revenue sharing ($6 billion), Housing and Community Development Act, and Comprehensive Employment and Training Act (CETA).

These three programs share certain general characteristics. Funds flow from Washington to the state-local level on the basis of a formula for allocation. Recipient governments have considerable discretion to spend funds within broad

TABLE 5

National Legal Services Corporation Specialized Litigation and Support Centers

Center for Law & Education, Inc.
6 Appian Way, Gutman Library, 3rd Floor
Cambridge, MA 02138
617/495-4666

Center on Social Welfare Policy & Law
95 Madison Avenue, 7th Floor
New York, NY 10016
212/679-3709
821 Fifteenth Street, NW, Suite 638
Washington, DC 20005
202/347-5615

Food Research and Action Center (FRAC)
2011 Eye Street, NW, Suite 700
Washington, DC 20006
202/452-8250

Handicapped People's Legal Support Unit
373 Park Avenue, South, 7th Floor
New York, NY 10016

Indian Law Backup Center, Native American Rights Fund
1506 Broadway
Boulder, CO 80302
303/447-8760

Legal Services Corporation
733 Fifteenth Street, NW
Washington, DC 20005
202/376-5100
Program Support 202/376-2508

Mental Disability Legal Resource Center
ABA, 1800 M Street, NW
Washington, DC 20036
202/331-2240

Migrant Legal Action Program
806 Fifteenth Street, NW, Suite 600
Washington, DC 20005
202/347-5100

National Clearinghouse for Legal Services
500 North Michigan Avenue, Suite 2220
Chicago, IL 60611
312/353-2566

National Consumer Law Center, Inc.
11 Beacon Street
Boston, MA 02108
617/523-8010

National Economic Development Law Project
2150 Shattuck Avenue, Suite 300
Berkeley, CA 94704
415/548-2600

National Employment Law Project
423 West 118th Street
New York, NY 10027
212/866-8591

National Health Law Program
2401 Main Street
Santa Monica, CA 90405
213/392-4811

National Housing Law Project
2150 Shattuck Avenue, Suite 300
Berkeley, CA 94704
415/548-9400
East: 2000 P Street, NW, Suite 410
Washington, DC 20036
202/452-8050

National Juvenile Law Center
3701 Lindell Boulevard
St. Louis, MO 63108
314/533-8868

National Legal Aid and Defender Association
2100 M Street, NW, Suite 601
Washington, DC 20037
202/452-0620

National Para-Legal Institute
2000 P Street, NW, Suite 600
Washington, DC 20036
202/872-0655

National Senior Citizens Law Center
1709 West 8th Street
Los Angeles, CA 90017
213/483-3990
East: 1200 15th Street, NW, Suite 500
Washington, DC 20005
202/872-1404

functional areas. All three programs provide opportunities to citizens, consumers, and advocates to participate in planning for the allocation of funds. As handicapped citizens and their advocates learn to view these funds in relation to the total budget process at the state and local level, they can begin to influence general policies and resource distribution.

Comprehensive Employment and Training Act (CETA)

CETA funds flow to state and local "prime sponsors" from the Department of Labor. Focus of the programs is on training for unemployed and underemployed populations, providing support services (e.g., child care, transportation) to trainees and workers, and creating new jobs by providing salaries for workers employed in public service jobs. The third objective may offer funding opportunities to P&A systems. For instance, a P&A system could receive funds to train and employ workers as paralegals or citizen advocates. Some P&A systems currently accessing CETA resources for personnel are Alaska, Delaware, Rhode Island, and Washington state.

The Youth Employment and Demonstration Projects Act of 1977 (P.L. 95-93) authorized $1.5 billion additional program support to the Department of Labor focused on low income youth experiencing difficulty in penetrating the labor market. Public and private nonprofit human service programs are eligible for support through Youth Incentive Entitlement Pilot Projects, Youth Community Conservation and Improvement Projects, and Youth Employment and Training Programs. Proposed regulations appeared in the *Federal Register*, September 16, 1977.

INFORMATION SOURCES: CETA

State prime sponsor or manpower agency or Office of the Governor; State Manpower Services Council;

Local prime sponsors;

Regional Assistant Director for Manpower, U.S. Department of Labor;

Employment and Training Administration, U.S. Department of Labor 601 D Street, NW, Washington, DC 20213 202/376-6366;

Comprehensive Employment and Training Act (CETA) of 1973 (P.L. 93-203); as amended, P.L. 93-567 and 94-444;

Youth Employment and Demonstration Projects Act of 1977 (P.L. 95-93);

Federal Register, September 16, 1977, Youth Programs under CETA; Title 29 of the Code of Federal Regulations, Parts 94-99;

A Guide to Seeking Funds from CETA: A Booklet to Assist Individuals and Organizations to Learn How to Apply for CETA Monies. U.S. Department of Labor, Employment Standards Administration, Women's Bureau, Washington, DC 20210;

A Planning Charter for the Youth Employment and Demonstration Projects of 1977. U.S. Department of Labor, Employment and Training Administration, Office of Youth Programs, Washington, DC;

CETA—A Citizen's Action Guide. Center for Community Change, 1000 Wisconsin Avenue, SW, Washington, DC 20001 202/338-3565.

Community Development Block Grants

Community development funds are available under Title I of the 1974 Housing and Community Development Act, P.L. 94-383, and its amendments, P.L. 95-128. This program distributes over $2 billion annually to state and local governments. Large urban areas (population of 50,000 or more) are automatically eligible for a share of the funds. Smaller, less populous areas may compete for funds available to both states and localities. In addition, the Secretary of Housing and Urban Development may reserve 2% of program appropriations for specific discretionary projects.

Up to 20% of the Title I funds available to any community may be used for public services not otherwise available and which are responsive to the needs of an area's residents. Title I is not a housing program; it provides for planning and development of neighborhood services and facilities. The law specifically requires communities to assess and meet the special needs of handicapped and elderly residents. P&A systems could legitimately receive community development public service funds for services to area residents. In addition, these funds may be used as the local share to match federal funds such as Title XX.

In order to receive Title I funds, a locality must develop an annual plan. The chief executive of the area (e.g., the major) has primary responsibility for the plan but must also involve the local legislative body (e.g., city council) and local citizens.

Information Sources: Title I

Chief executive of state-local government

Regional Office of Housing and Urban Development

Department of Housing and Urban Development
Office of Independent Living
HUD Building
Washington, DC
202/755-6032

Federal Register, October 25, 1977

General Revenue Sharing

Authorizing legislation for General Revenue Sharing (GRS) under the 1976 Amendments to the State and Local Fiscal Assistance Act (P.L. 94-488) added handicapped persons as a new category of people protected from discrimination. This provision is important because the general nondiscrimination provision (Section 122), which covers race, color, sex, age, and national origin, contains a strict timetable for processing complaints, attaining compliance, and automatic suspension of payments. P&A systems will want to examine GRA-funded programs for compliance not only with Section 504 of the 1973 Rehabilitation Act (P.L. 93-112) but the more proscriptive standards of P.L. 94-488.

NEW ENTITLEMENTS: MIKVA CHILD SSI REFERRAL

Disabled children enrolled for Supplemental Security Income (SSI), in addition to receiving cash payments through the Social Security Administration, can soon look to a new state level service component established by legislation late in 1976. Section 501 (the Mikva Amendment) of P.L. 94-566, the Unemployment Compensation Act, authorized $30 million in 100% federal formula grant funds to any state agency designated by the governor to be responsible for referring child SSI recipients to appropriate services, for accessing services in the child's behalf, and for providing direct services in some instances.

The program merits the close attention of advocacy groups for developmentally disabled persons, DD councils, and other advocates for disabled children, because:

- The target population includes many DD children.
- The program requires each governor to designate some state agency to perform functions of resource-linking, service-accessing, broker advocacy—concepts familiar to DD councils. In many states, Maternal Child Health-Crippled Children's Service (MCH-CCS) agencies will administer the program, even though MCH-CCS agencies traditionally have not performed these functions. DD council assistance may be valuable in early policy decisions about program delegation and in planning for coordination with other provider agencies.
- The monitoring, follow along, and case management functions of the new program may overlap with DD protection and advocacy systems. Careful planning and informed decision making can avoid wasteful duplication. In some instances, the P&A system could be designated on a contract basis to perform this monitoring function.

Program Scope Set Forth in Legislation

The governor-designated state agency has the following responsibilities for each SSI recipient under age 16:

- Assure "appropriate counseling" to the disabled child and her or his family.
- Establish an individualized service plan for the child.
- Make prompt referral of the child to appropriate medical, educational, and social services.
- Monitor adherence to the individualized service plan.
- Review quarterly the child's need for and utilization of services.

Agency responsibilities to all SSI recipients under 16 could be variously described as case management, follow along, or broker advocacy. However, only 10% of the funds may be used for these functions.

Overshadowing these service-accessing, coordination, and monitoring functions are mandates to provide medical, social, developmental, and rehabilitative services to two subgroups of the SSI child population: all SSI recipients 6 years of age and under, and some older children who "have never attended public school and require preparation to take advantage of public educational services . . . where such services reasonably promise to enhance the child's ability to benefit from subsequent education or training" (Section 501).

Of the $30 million allocation by formula grants to states, 90% must be spent on providing services to SSI recipients under age 7 and to the qualified group of older children.

Current SSI roles include an estimated 91,400 children under age 16 who are entitled to counseling, individual service plans, referral, and follow along under the new program. Of that group 18,000 are children under age 7 for whom funds are available to provide (directly, or through purchase or contract) a full range of services.

HEW regulations implementing the program were promulgated in the *Federal Register*, December 16, 1977. The regulations specify that the state plan will give evidence that cooperative arrangements with existing agencies serving disabled children have been made.

Accessing Funds

P&A systems wishing to access funding through the SSI program may find the following plan of action useful:

Contact the governor's office to find out if an administering agency has been designated and if a state plan has been approved.

Identify and contact the agency head and the agency staff responsible for developing the state plan.

Find out specifics of tentative implementation plans.

Evaluate the resources of the designated agency in relation to this program. What assistance do they need to make the SSI child referral program work in your state? How can the P&A provide support? referrals? monitoring? task group work?

Negotiate written cooperative interagency agreements, which are required by HEW guidelines.

Investigate the possibility of designating the P&A system as a lead agency for coordination and advocacy for individual service plans.

INFORMATION ON FEDERAL FUNDING SOURCES

Among the directories, catalogues, and guidebooks available to those tracking down federal dollars are:

Catalog of Federal Domestic Assistance
Office of Management and Budget
Superintendent of Documents
Government Printing Office
Washington, DC 20402

Grants: How to Find Out About Them and What To Do Next
Virginia White
New York, Plenum Press, 1975

Grants and Contracts in Major HEW Health Agencies
National Health Council
1740 Broadway
New York, NY 10019

Guide to Federal Resources for the Developmentally Disabled
Federal Program Information and Assistance Project
1522 K Street, NW
Washington, DC 20005

How to Get Government Grants
Philip Des Marais
Public Service Materials Center
355 Lexington Avenue
New York, NY 10017

Resource Notebook
United Cerebral Palsy Association, Inc.
Clarke Ross
Governmental Affairs
425 I Street, NW
Washington, DC 20001
202/638-6170

The Grantsmanship Center News
1015 W. Olympic Boulevard
Los Angeles, CA 90015
(published eight times per year, annual subscription $15/year; recent titles include "Program Planning and Proposal Writing," "Researching Foundations," "The Catalogue of Federal Domestic Assistance," and "Breaking Through the Maze: Title XX of the Social Security Act.")

Where The Money is ($5.00)
National Center for Community Action
1711 Connecticut Avenue, NW
Washington, DC 20009
202/667-8970

TABLE 6

Regional Collections of the Foundation Center

ALABAMA
Birmingham Public Library
2020 Seventh Avenue, North
Birmingham 35203

ALASKA
University of Alaska
3211 Providence Street
Anchorage 99504

ARIZONA
Tucson Public Library
Main Library
200 S. Sixth Avenue
Tucson 85701

ARKANSAS
Little Rock Public Library
Reference Department
700 Louisiana Street
Little Rock 72201

CALIFORNIA
University Research Library
Reference Department
University of California
Los Angeles 90024

San Diego Public Library
820 E Street
San Diego 92101

COLORADO
Denver Public Library
Sociology Division
1357 Broadway
Denver 80203

CONNECTICUT
Hartford Public Library
Reference Department
500 Main Street
Hartford 06103

FLORIDA
Jacksonville Public Library
Business, Science, and Industry Department
122 North Ocean Street
Jacksonville 32202

Miami — Dade Public Library
Florida Collection
One Biscayne Boulevard
Miami 33132

GEORGIA
Atlanta Public Library
126 Carnegie Way N.W.
Atlanta 30303
(also covers Alabama, Florida, South Carolina, and Tennessee)

HAWAII
Thomas Hale Hamilton Library
University of Hawaii
Humanities and Social Sciences Division
2550 The Mall
Honolulu 96822

IDAHO
Caldwell Public Library
1010 Dearborn Street
Caldwell 83605

ILLINOIS
Sangamon State University Library
Shepherd Road
Springfield 62708

INDIANA
Indianapolis — Marion County Public Library
40 East St. Clair Street
Indianapolis 46204

IOWA
Des Moines Public Library
100 Locust Street
Des Moines 50309

KANSAS
Topeka Public Library
Adult Services Department
1515 West Tenth Street
Topeka 66604

KENTUCKY
Louisville Free Public Library
Fourth and York Streets
Louisville 40203

LOUISIANA
New Orleans Public Library
Business and Science Division
219 Loyola Avenue
New Orleans 70140

MAINE
University of Maine at Portland Gorham
Center for Research and Advanced Study
246 Derring Avenue
Portland 04102

MARYLAND
Enoch Pratt Free Library
Social Science and History Department
400 Cathedral Street
Baltimore 21201
(also covers District of Columbia)

MASSACHUSETTS
Associated Foundation of Greater Boston
294 Washington Street, Suite 501
Boston 02108

Boston Public Library
Copley Square
Boston 02117

MICHIGAN
Henry Ford Centennial Library
15301 Michigan Avenue
Dearborn 48126

Purdy Library
Wayne State University
Detroit 48202

Grand Rapids Public Library
Sociology and Education Department
Library Plaza
Grand Rapids 49502

MINNESOTA
Minneapolis Public Library
Sociology Department
300 Nicollet Mall
Minneapolis 55401
(also covers North and South Dakota)

MISSISSIPPI
Jackson Metropolitan Library
301 North State Street
Jackson 39201

MISSOURI
Kansas City Public Library
311 East 12th Street
Kansas City 64106
(also covers Kansas)

The Danforth Foundation Library
222 South Central Avenue
St. Louis 63105

Springfield — Greene County Library
397 East Central Street
Springfield 65801

MONTANA
Eastern Montana College Library
Reference Department
Billings 59101

NEBRASKA
W. Dale Clark Library
Social Sciences Department
215 South 15th Street
Omaha, 68102

NEW HAMPSHIRE
The New Hampshire
Charitable Fund
One South Street
Concord 03301

NEW JERSEY
New Jersey State Library
Reference Section
185 West State Street
Trenton 08625

NEW MEXICO
New Mexico State Library
300 Don Gaspar Street
Santa Fe 87501

NEW YORK
New York State Library
State Education Department
Education Building
Albany 12224

Buffalo and Erie County Public
Library
Lafayette Square
Buffalo 14203

Levittown Public Library
Reference Department
One Bluegrass Lane
Levittown 11756

Rochester Public Library
Business and Social Sciences
Division
115 South Avenue
Rochester 14604

NORTH CAROLINA
William R. Perkins Library
Duke University
Durham 27706

OKLAHOMA
Oklahoma City Community
Foundation
1300 North Broadway
Oklahoma City 73103

Tulsa City-County Library System
400 Civic Center
Tulsa 74103

OREGON
Library Association of Portland
Education and Psychology
Department
801 S.W. Tenth Avenue
Portland 97205

PENNSYLVANIA
The Free Library of Philadelphia
Logan Square
Philadelphia 19103
(also covers Delaware)

Hillman Library
University of Pittsburgh
Pittsburgh 15213

RHODE ISLAND
Providence Public Library
Reference Department
150 Empire Street
Providence 02903

SOUTH CAROLINA
South Carolina State Library
Reader Services Department
1500 Senate Street
Columbia 29211

TENNESSEE
Memphis Public Library
1850 Peabody Avenue
Memphis 38104

TEXAS
The Hogg Foundation for Mental
Health
The University of Texas
Austin 78712

Dallas Public Library
History and Social Sciences
Division
1954 Commerce Street
Dallas 75201
(also covers Arkansas, Louisiana, New Mexico, and Oklahoma)

El Paso Community Foundation
El Paso National Bank Building,
Suite 1616
El Paso 79901

Minnie Stevens Piper Foundation
201 North St. Mary's Street
San Antonio 78205

UTAH
Salt Lake City Public Library
Information and Adult Services
209 East Fifth Street
Salt Lake City 84111

VERMONT
State of Vermont Department
of Libraries
Reference Services Unit
111 State Street
Montpelier 05602

VIRGINIA
Richmond Public Library
Business, Science, & Technology
Department
101 East Franklin Street
Richmond 23219

WASHINGTON
Seattle Public Library
1000 Fourth Avenue
Seattle 98104

Spokane Public Library
Reference Department
West 906 Main Avenue
Spokane 99201

WEST VIRGINIA
Kanawha County Public Library
123 Capitol Street
Charleston 25301

WISCONSIN
Marquette University Memorial
Library
1415 West Wisconsin Avenue
Milwaukee 53233
(also covers Illinois)

WYOMING
Laramie County Community
College Library
1400 East College Drive
Cheyenne 82001

PUERTO RICO
Consumer Education and Service
Center
Department of Consumer Affairs
Minillas Central Government
Building North
Santurce 09908
(covers selected foundations)

MEXICO
Biblioteca Benjamin Franklin
Londres 16
Mexico City 6, D.F.
(covers selected foundations)

Note. From "Foundation Center Regional Collections" by L. Katzowitz, in *Researching Foundations: Part I*, 1978, 2-7, 24. (Reprinted from the *Grantsmanship Center News*, issue 12.) Copyright 1974, 1975, 1978 by The Grantsmanship Center.

A number of periodicals report on the details of changes in federal policy and availability of federal funds. *Commerce Business Daily* (CBD) reports on requests for proposals (RFPs) issued by the federal government. A clipping and abstracting service of Morris Associates (1346 Connecticut Avenue, NW, Washington, DC 20036) scans CBD for HEW-oriented projects and mails these listings to subscribers.

Morris Associates also publishes *Federal Funding File Bulletins, MH-MR Report,* and *Health Systems,* which give periodic updates on legislation, regulations, and funding in the health field. The firm also provides training seminars.

A resource for more general information is Government Information Services, 752 National Press Building, Washington, DC 20045. This company maintains a computer data bank on federal assistance programs, publishes *Local Government Funding Report* and *Federal Register Report,* and provides seminars and training sessions.

INFORMATION ON PRIVATE FUNDING FOUNDATIONS

Some of the most readable and helpful material on this topic is available in *The Grantsmanship Center News* (1015 W. Olympic Boulevard, Los Angeles, CA 90015). A series of articles from the *News* containing information about private foundations and how to get their support has been reprinted by the Grantsmanship Center. "Researching Foundations: Part I" and "Researching Foundations: Part II" describe the use of resources such as the Foundation Center, The Foundation Directory, and the Foundations Grants Index. One article, "Foundation Center Regional Collections," by Lauren Katzowitz, describes the research resources of the regional collections of the Foundation Center. A list of these regional centers is provided in Table 6. Materials available at these locations include publications *(Foundation Directory* and *Foundation Grants Index)* as well as listings of organizations filing as private foundations and annual reports of foundations.

Materials available at these locations include publications *(Foundation Directory* and *Supplement: Foundation Grants Index)* as well as listing of organizations filing as private foundations and annual reports of foundations.

The *Foundation Directory,* published by the Foundation Center, can be ordered for $35.00 from Columbia University Press, 136 S. Broadway, Irvington, NY 10522. It lists the 2,818 largest foundations in America, which award 80% of all foundation grants. Complete descriptive information on each foundation includes statement of purpose, range of grants available, subject interest, grant application format, deadline, and contact names and addresses.

In addition, many states and regional areas have developed directories (e.g., *The Guide to Foundations of the Southeast, Directory of Foundations in Massachusetts).* Contact your state attorney general's office to inquire about specialized directories in your state.

INFORMATION: WRITING GRANTS

Whether you seek public or private funds, a good tool for the novice grant writer is the *Grantsmanship Workplan* (The Eckman Center, PO Box 621, Woodland Hills, CA 91365, approximately $25). This highly readable document provides essential information about a grantsmanship strategy and mechanics: analyzing a request for proposals (RFP), writing project narrative, presenting a evaluation scheme, and developing a budget.

CONCLUSION

The crisis in "unnatural resources" is not necessarily a matter of shortage of resources. The crisis for P&A systems may center on the difficulty of untangling the information knot surrounding both public and private resources. P&A systems operating on minimum formula allocations will do well to consider hiring or pirating specialized help to develop program support. The fund-seeking assignment can be made to a staff person, to a consultant (on contract basis), or to a concerned volunteer or group of volunteers (e.g., task group of your advisory committee).

References

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Morris Associates. *Federal Funding File Bulletins,* 1976, *3*(26).

National Clearinghouse for Legal Services. Illinois Bar Association issues opinion on state welfare department's client disclosure requirements as condition for receipt of Title XX funds. *Clearinghouse Review,* 1977, *11,* 659.

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Social Legislation Information Service. *Washington Social Legislation Bulletin,* 1977, *25*(1), 4.

Tomlin, L. *Lily Tomlin on stage.* New York: Arista Records, Inc., 1977. (Sound Recording)

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Part Four

Pursuits

chapter 17

Training Attorneys and Advocates For Protection and Advocacy Systems

Marcia Pearce Burgdorf

Any training program for lawyers, advocates, and paralegals in the protection and advocacy (P&A) systems is going to have four objectives. The objectives include education as to the nature and problems of developmentally disabled persons, development of advocacy skills, development of ethics, and analysis of the legal issues.

First Objective: Education as to the Nature and Problems of Developmentally Disabled Persons

The first, and perhaps the most important objective, is educating the individual advocates about developmental disabilities. Any new staff person coming into the P&A system needs to know: What does *developmental disabilities* mean? What does *autism* mean? What does *cerebral palsy* mean? What does *mental retardation* mean? People without experience in developmental disabilities—and this certainly applied to lawyers as well as people from other professions—will hold the same stereotypes as the general public. At the Developmental Disabilities Law Project, we have seen, in the various individuals that have come into our program to train, a manifestation of almost all the stereotypes that society has applied to developmentally disabled persons. For example, many students and professionals coming into our program did not realize that all retarded people can learn. Many people believed that epilepsy is always hereditary and many other people believed that everyone with cerebral palsy is disabled to the same degree.

In educating advocates about developmental disabilities, one of the key experiences necessary is to have them meet persons who are disabled. In the advocacy program that we now run, we do not have many developmentally disabled clients coming into the office. Thus, we have to go out and meet them. In teaching advocates about developmentally disabled persons, it is important to observe disabled individuals in more than one setting. One would want the advocate to examine how people are functioning in an educational setting, how they are functioning in institutions, in the community, in group homes, and in independent living situations. It is important to try to get a cross-section of the various types of disabilities, as well as different levels of functioning, so that an advocate trainee can see that the quality of the program an individual is participating in can significantly affect his or her functioning level. These are extremely desirable experiences for advocates in training. In our program, we set aside a short period of time—one to three weeks—for taking trainees on a variety of field trips. We found that it is much better to concentrate on these experiences than to spread the training over a long period of time.

Another important factor in trying to educate advocates about the problems of developmentally disabled people is to remember that people have not often had previous contact or experience with severely and profoundly handicapped people. This lack of contact can cause individuals to have very emotional experiences on field trips. When training advocates, one should make sure to provide the proper follow-up in order to deal constructively with this situation. Individu[illegible] need to sit down and talk about their own personal reactions to seeing severe[illegible] and profoundly retarded people in institutions, to seeing people with self-abu[illegible]e behavior, to seeing people who cannot talk or respond, or who do not have social impulses that we have been trained to think that every normal person has. When trainees do not have this opportunity to talk about their personal feelings, we have found that their feelings often prohibit them from really being good advocates in behalf of disabled people. Some role playing can be helpful in this debriefing session.

Thus, the first objective in training is to educate the advocates about the nature of disabilities and the problems of developmentally disabled persons by actually giving them exposure to their clients. Working and talking with developmentally disabled people themselves, as well as with their parents and families, are essential to develop a real human understanding of their abilities, their needs, and their problems.

Second Objective: Development of Advocacy Skills

The second objective in training is developing advocacy skills. Whether the person is a paralegal or a lawyer, there are four basic skills that are necessary in the advocacy system: interviewing, counseling, negotiation, and advocacy at formal hearings. There are a variety of ways that an advocacy agency can divide up the responsibilities. For example, if you have the luxury of having four or five staff members, you may well want the staff to specialize and have only one person doing the interviewing, or the interviewing and the counseling, and have two of the staff doing the advocacy at formal hearings, and have another person doing the negotiation. An alternative would be to train the whole staff and give them some experience in all four skills. This decision depends on the number of personnel that you have as well as their individual abilities. In some cases, it may be cost-effective to have people specialize; in others it might be more helpful to have everyone doing a little bit of everything. All persons entering the field of developmental disabilities need some training and skills development. In advocating for developmentally disabled people, there are particular problems that one will encounter even if he or she has extensive experience in related areas. Interviewing a developmentally disabled person who cannot communicate very well is very different, for example, from interviewing or working with a low-income client.

It is important to try to give your personnel some opportunities to develop skills in interviewing disabled people and in counseling them. The philosophical concept of exercising individual rights means that an advocate is to give clients the chance to choose alternatives—to choose whether they want to live in a group home, or whether they want to live in a family home, or whether they want to stay in the institution. In most instances, law school has given very little training to lawyers on how to counsel clients in the "normal" population. In the area of developmental disabilities, counseling training is even more important because some of the standard methods of counseling people—simply asking them questions and asking them to choose—will not necessarily produce valid answers. It may not be enough to sit down with developmentally disabled clients and in a one-hour session say, "Do you want to have this operation?" or, "Do you want to move out of the institution?" You may need to establish a personal relationship with clients and you may need to work with the individuals over a period of time so that you can really be sure that they do understand what the questions are and the implications of the choices that they make; most important, you need to insure that they freely make the choice that you are giving them. It is very important to help advocates develop their skills in counseling and interviewing so they can properly represent disabled people.

Videotape and role playing can be used in developing skills very successfully. Sometimes role playing is viewed as an academic exercise, and people feel very uncomfortable playing roles, but it is a useful strategy for helping advocates understand developmentally disabled people. Assigning advocates the role of the head of the institution, or the houseparent, or even a developmentally disabled person, gives them the good experience of looking at needs from another perspective. Videotape is one of the best teaching tools available. An actual interview or counseling session can be videotaped, with permission, of course, for training purposes. Viewing the tapes should be followed by the instructor discussing how the trainee could have conducted the session better, the mistakes that we made, and the good things they want to reinforce.

Finally, while it is important to do some initial skills training, it is also important to go back at certain periods over the course of a year or two for some retraining. Staff members may lose their perspective of the P&A system by becoming absorbed in one of its activities. For example, the administrator of the program may get totally involved in fund raising and administration and lose sight of the goals of advocacy. The whole agency may become sidetracked by a preponderance of cases of one type and lose sight of other needs that it can help to meet. It is very good to go back and brush up on the four basic skills and to try to maintain your perspective.

Third Objective: Development of Ethics

The third objective in training advocates for developmentally disabled people is to develop a set of ethics. It is very important that advocates be able to help their clients make choices, but they must also make important decisions on how to represent clients. And they must be trained to make essentially the right decision. The "right decision" is not based on any particular moral or principle. However, many of the decisions that the advocate is going to have to make are very tough decisions.

We currently have two cases at the Law Project presenting difficult decisions. In one case, a mentally retarded women was referred to us by an institution. She has lived in the institution most of her life, and she has had since birth a deformed jaw. Because of her deformity, she has not been able to learn to speak, although she is in a public school program and is doing quite well. The social worker at the institution referred her to us because she felt that this person could benefit from surgery to correct the condition of the mouth and the tongue so that she could eventually learn to speak. This woman is obviously intelligent and is frustrated by the fact that she is not able to communicate verbally. She really has been cut off from a major part of her life. We were going to see if we could advocate in her behalf for some surgery, or at least get some expert opinion on whether this would be beneficial. We have represented this woman for about a year and a half and in the process have accompanied her and her social worker to a variety of medical facilities throughout the country to try to define her problem and possible solutions. We have now learned that there is probably a 50/50 chance that she could be helped by major surgery on the mouth, jaw, and tongue. Even with surgery, however, there is only a 30% chance that she will be able to talk, although she will not drool, and some other unattractive physical problems will be eliminated. The surgery would be painful and very time-consuming (several years). The woman can communicate a little bit now.

What is our ethical responsibility as advocates to let her make the choice about going ahead with the surgery? Our staff is concerned and has decided that we need to continue to take whatever time is necessary to go back and help the woman to understand and help her to make the choice. We also feel strongly that it is essential for us as advocates to avoid making the choice for her until we have tried over a considerable amount of time, with the help of her friends and persons experienced in communications problems, to let her make that choice herself. In most instances, it is not that disabled persons do not know how to communicate, it is that we do not know how to listen!

There will not be very many instances where people can tell you what the "right answer" is, and it is a difficult process to work through. It is important in the training of staff that you discuss ethical questions, that you discuss what people's beliefs are about disabled clients they are serving, and that you sensitize them to the fact that the disabled persons themselves, whenever possible, should be making decisions in their own behalf. The presumption should be that the individual is competent; that the individual can raise a family; that he or she can hold down a job until proven otherwise. The presumptions of society and agency people are that developmentally disabled people are not competent. We as advocates have to shift that balance and presume that they can until proven otherwise.

One other example of a situation requiring ethical decisions concerns the fact that almost all your referrals will come in from third parties. What do you do as an advocate in that situation? Whenever possible, even with third party referrals, there is clear ethical responsibility for the advocates to talk to the disabled person who is involved in the complaint and to the groups of people that the complaint would affect. We had a case about a year and a half ago of a disabled 17-year-old boy whose parents came in. The parents wanted us to represent the son at a due process hearing because they felt that the child was not properly placed in the public school system. One of the questions that we asked them during the interview (the son was not present) was, "What does your son think about this?" Their response was, "We don't know, and we don't understand why that is important." We felt that is was very important, and subsequently set up an interview with the son. The son did not want to change schools. He felt that where he was was very good for him and that the reason that the parents did not like it had more to do with the changing racial patterns in the area than with the education. He was clearly not of the same mind as the parents. With any complicated ethical questions, we must ask not only what our responsibilities are as advocates, but must determine clearly what the choices are of the disabled people themselves.

Fourth Objective: Analysis of the Legal Issues

The final objective in the training of advocates is having them understand the legal issues. The legal issues are complex and difficult. One of the real problems in the area of the rights of handicapped people is the fact that there are so many rights and so many issues, and we have only begun to address a few of them. We have clearly established the rights to education and nondiscrimination, and we are beginning to clarify the rights to employment and treatment as well as many more. But we are just really beginning to look at many other issues that the advocacy systems are going to have to deal with: marriage, insurance, housing, zoning—there are hundreds of legal issues. One of the most difficult jobs facing P&A systems is to give trainees a grasp of all those issues. Realistically, you cannot. There are too many interests that are very complex. So the fourth objective of training, understanding the legal issues, will require continuous training throughout the operation of the P&A system. Advocates must have time to read, look at their cases, and to keep abreast of what is happening.

Understanding the issues is probably the most difficult objective of training. I recommend to you, as people who are administering the P&A system, that you take time with your staff to talk among yourselves and to share what you have learned with one another. There has been a real feeling in our agency in the past that to spend time in talking with one another was wasteful. However, we now try to set a time aside weekly or biweekly because we feel that meeting to share substantive information is really one of the most important uses of our time. We can help one another learn, for example, how the due process hearings procedure in the education area is impacting on the institutionalization of children. This issues are related to one another and these interrelationships need to be raised in order to provide the best advocacy possible.

The underpinning of the P&A system is the advocates' understanding clearly not only what the legal issues are, but also what an advocate's proper remedies are. The job is complex because we are dealing not just with the difficulites of understanding developmentally disabled people—people who are not used to having advocates, people who are not used to complaining or objecting to how they are being treated—but also with all different kinds of professions—doctors, psychologists, educators, and social workers, among others. Advocates need to learn their jargon and get a feel for how to deal with them. It would be a mistake for people in charge of P&A systems to assume that their staffs are sufficiently prepared by their experience in related fields to advocate effectively in the area of developmental disabilities. Some training for all advocates, to achieve the four objectives I have discussed, will help sensitize staff members to the particular needs of developmentally disabled persons and the legal and ethical issues involved in advocating in their behalf, and will help them acquire the necessary skills to be the best advocates possible.

chapter 18

The Gun on the Table: Developing High-Level Litigation Capability

Edward A. Stutman

In *Gulliver's Travels*, Jonathan Swift paints a very disparaging picture of lawyers (1726/1960). Gulliver is traveling in the land of the Houyhnhnms and engages himself in conversation with a man who asks him to describe his country, England. Gulliver, in the course of his description, talks about lawyers. He says, "There was a society of men among us, bred up from their youth in the art of proving by words multiplied for the purpose, that white is black, and black is white, according as they are paid. To this society, all the rest of the people are slaves." Gulliver goes on to describe how lawyers operate, giving an example. He says, if he has a cow and his neighbor wants it, the neighbor has the advantage because lawyers are better at defending falsehood than justice. Gulliver goes on to point out that the only way he can win is to pay his adversary's lawyer double the fee and get him off the case, or to have his own lawyer make his cause appear unjust and thereby win the favor of the bench. The Houyhnhnm man observes that it is a pity that lawyers, with "such prodigious abilities of mind," are not encouraged to be "instructors of others in wisdom and knowledge." Gulliver says,

> In answer . . . I assured his Honour, that in all points out of their own trade they were usually the most ignorant and stupid generation among us, the most despicable in common conversations, avowed enemies to all knowledge and learning, and equally disposed to pervert the general reason of mankind in every other subject of discourse, as in that of their own profession. (p. 202)

Gulliver's opinion of lawyers is shared by some people today, but I feel certain you will not allow such unsubstantial views to diminish the role of legal advocacy in the advocacy system about to be designed. The experience of the Public Interest Law Center in Philadelphia during the past three years confirms the utility of having a "gun on the table." The Law Center has a Developmental Disabilities Law Project, funded by the state developmental disabilities (DD) council and our advocacy network, and staffed by four lawyers. We also have social science resource people on the staff—people who are not lawyers, but without whom we could not function. The past president for the National Association for Retarded Citizens, for example, gives some very valuable technical assistance.

Thomas Gilhool, Chief Counsel of the DD Law Project, has published an article (1976) which presents the concept of public interest litigation and the uses of courts and lawyers in a way that everyone can, and you should particularly, understand. The entire article should be studied by those planning protection and advocacy (P&A) systems according to Section 113 of the Developmentally Disabled Assistance and Bill of Rights Act (DD Act, P.L. 94-103), especially the proposal on page 162 for statewide legal advocacy centers. Gilhool begins his article by rearticulating the reasons that some parties continually win in litigation, while others lose, a question raised by Marc Gallanter in a 1974 article. One reason some parties win is that they are repeaters, and the repeat players have decisive advantages over the one-shot players. The stakes are higher for the one-shot players. The repeat players will be back in that forum again; they can trade off one case against another case. The concept of the repeat player versus the one-shot player is very important to all of you because of the need for ongoing legal assistance in a highly structured way. You cannot rely any more on "Uncle Charlie," the lawyer, to do advocacy work for the local Association for Retarded Citizens (ARC), or the local chapter of American Citizens with Learning Disabilities, or the local chapter of United Cerebral Palsy. You cannot do that any more—not because Uncle Charlie is uninterested, but because he lacks sufficient expertise; the situation requires a different kind of capability.

Gilhool then sets forth the reasons for "going to court," and by logical inference, for maintaining a high-level litigation capability.

Going to Court

Historically, people go to the court to change rules. *Pennsylvania Association for Retarded Children* v. *Commonwealth of Pennsylvania*[1] was a case that set out to change the rule that excluded retarded children from public education in Pennsylvania. Incidentally, that case ended in negotiated settlement. This corroborates the theory that the negotiation-litigation dichotomy is really fictitious. *Mills* v. *Board of Education of the District of Columbia,*[2] an education case, was also a case to change the rules. The new Education for All Handicapped Children Act (P.L. 94-142) was partly a result of this court action. The outcome of *Mills*, discussed in the regulations to P.L. 94-142, illustrates the impact that litigation can have on legislation, that is to say, on changing rules.

Another reason for litigation is to create new forums for articulating ideas. For example, one result of *Pennsylvania Association for Retarded Children (PARC)* was that new mechanisms were created to oversee special education in the state of Pennsylvania. The existing forums allowed negotiating with the state exclusively. When the local ARCs could no longer go to the state department of education and get what they wanted, new forums and new mechanisms had to be created. What came out of PARC was a set of masters, people appointed by the court to oversee the implementation of the order. The "due process hearing" also was created by *PARC*. That, of course, is found now in P.L. 94-142, the Education of All Handicapped Children Act. In the Willowbrook deinstitutionalization case, a new mechanism, the Willowbrook Review Panel, was created to oversee the disbursement of people in Willowbrook (see Chapter 21 of this book). The court creates new forums because other forums no longer work.

Another important reason that people go to court is to focus attention on problems. The courtroom has been, since the advent of television, overrated as a stage. Yet, the courtroom is a stage where people perceive new ideas or new perspectives and destroy stereotypes. At the DD Law Project in Philadephia, we make sure when we are involved in litigation, that the media are aware of what is going on in the courtroom and why. We have to make sure the attention is focused where we want it.

The other reason that a lot of people go to court is that courts, unlike legislatures, have to deal with principles. Courts cannot give parties only some of their rights, as legislatures do. Courts have to give them all their rights. The principle itself will be established in court instead of a compromise, and the principle will determine the rights.

Another reason to go to court is to affirm the worth of the clients. Before *PARC*, a lot of people were in the closet, including parents of handicapped children and the individuals who were being denied education. Whatever they got, they got out of a sense of charity from the state or from their local Easter Seals Society, or other service groups. As a result of *PARC*, everybody started to assert their rights. The parents, the consumers, and the handicapped people themselves redefined their own worth in the process. No longer were rights and services a matter of charity; no longer could the people successfully be put in church basements.

As articulated by Gilhool, the multitude of reasons that can exist for going to court shows how necessary a tool for P&A systems is high-level litigation capability.

The Myth of the Negotiation-Litigation Dichotomy

The negotiation-litigation dichotomy is a myth. The issue is power: how to get it, how to keep it, how to use it most effectively, how to maintain it over a long period of time. The capability of performing high-level, broad-based, class action litigation is important in getting and using power. Capability in itself is a deterrent. For example, labor unions don't have to remind management constantly that they may strike. Everybody knows that labor unions can strike. That threat is always present in the course of negotiations. The capability to perform high-level litigation is something that must be in the repertoire of state protection and advocacy systems, just as the capability to strike is in the repertoire of the labor union when it negotiates.

That capability requires specialized, highly skilled attorneys. We know that the law is highly technical. We also know that the service delivery system for persons with developmental disabilities is highly technical. Working with the law and the service delivery system requires knowledge and lawyers who work in no other field but developmental disabilities. You need a gun on the table when you negotiate, and the most dangerous gun is one that isn't loaded.

Dr. Abram Chayes of Harvard has written about the concept of public interest litigation and how it evolved (1976). In traditional litigation, you have an identifiable plaintiff and identifiable defendent, and the proceeding is pretty much demarcated by the old rules we all know in law. But Dr. Chayes points out that public interest litigation is different:

> The party structure [in public interest litigation] is sprawling and amorphous, subject to change over the course of litigation. The traditional adversary relationship is suffused and intermixed with negotiating and mediating process at every point. The judge is the dominant figure in organizing and guiding the case, and he draws for support not only on the parties and their counsel, but on a wide range of outsiders—masters, experts, and oversight personnel. Most important, the trial judge has increasingly become the creator and manager of complex forms of ongoing relief, which have widespread effects on persons not before the court and require the judge's continuing involvement in administration and implementation. (p. 1284)

Dr. Chayes' point is that you don't have to worry about choosing between litigation and negotiation because under today's concept of public interest litigation, you are always in negotiation.

Beginning Litigation

Litigation, which begins for different reasons, also begins in different ways. Some cases get started by accident. A good example of that is *Wyatt* v. *Stickney*,[3] which was initiated by employees of an institution in Alabama who were interested in job security. Interest in treatment for residents in Alabama developed as the case proceeded. The case broadened, included more people, and eventually became the first real right-to-treatment litigation representing the interests of the residents of that particular state institution.

Litigation also gets started by persistence. A good example of that is *Donaldson v. O'Connor.*[4] Kenneth Donaldson had been in a Florida institution for 14 years. His case was in the Supreme Court, back down, up again, and back down again. But he hung on to what he knew was right for him. He found others who were equally persistent. The continual agitation and advocacy—his *own* continual agitation and advocacy—led ultimately to the Supreme Court action. We have illustration of that kind of persistence in our office, too. A blind woman was refused a teaching job in the Philadelphia public system in 1972. She wouldn't let the matter ride. Because of her persistence, that case went before the 3rd Court of Appeals, and she was successful. We have an education case right now involving a mother of two severely retarded children who has been fighting the school system for more years than she would probably care to admit. She said the law entitled the children to appropriate education, and they weren't getting it.

Litigation can arise because of research by advocacy or related groups. In Philadelphia, groups of disabled people conducted a lot of technical research regarding "Transbus." That research was a precursor to some litigation, which was largely based on research done by the disabled people themselves.

Lawyers can also initiate litigation. A lawyer who has some knowledge of the field could walk through a state institution and trip over 40 potential cases. A lot of litigation has begun just that way, but it is not the soundest method, because when your fist goes in, there is some other part of the bureaucracy that will go out, just as when you punch a sandbag, the sand will fill some other part of the bag. If you pick only one problem to solve, you never know how the bureaucracy is going to react to it. In the end, you might have another set of problems. The following two examples show why legal advocacy must be conducted with a sense of the consequences.

The first example is a case brought against an institution in Pennsylvania to outlaw peonage. Peonage means that the people in the institution were working without pay for the government. A lawyer observed that fact during a trip through the institution and went to court. The court said he was right. As a result, now the residents do not do anything because the state cannot pay them.

Another example is a case brought because the state of Pennsylvania was taking social security money from institutional residents without due process of law. So the court ordered the Department of Welfare to hold all the money in a big pot until they could decide how to fairly take the money. The state now has $60 million in that pot, and it needs that money. The way the court and state are going to deal with the problem is to institute guardianship proceedings against all the residents of state institutions. The aim is to prove that the residents

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are incompetent so the guardian can thereby take the money and pay the resident maintenance bills. Legal advocates have to respond.

Finally, litigation also develops through an organized strategic approach, which is the best way. Unfortunately, it is not the only way that is used. An example of an organized, strategic approach to litigation was the 1971 Pennsylvania Association for Retarded Children suit against Pennhurst state school and hospital. Action on the part of PARC was initiated because of inhumane conditions at Pennhurst. Although it was a very powerful advocacy group, the Pennsylvania ARC initially engaged in informal conversation with the Secretary of Education within the state Department of Public Welfare. For them to contemplate litigation was a major task. They met with Tom Gilhool and formulated a collective advocacy strategy. Rather than litigating in behalf of individuals at Pennhurst, PARC chose to represent the class of individuals in a right to education suit. Analyzing the consequences of closing Pennhurst, they concluded that there was no place in the community for the residents to go. Community facilities were not available and the schools were not educating retarded students. Thus, the twofold goal of this group of advocates in *Pennsylvania Association for Retarded Children* v. *Commonwealth of Pennsylvania* was to develop community residential facilities for handicapped people as stated in Section 504 of the 1973 Rehabilitation Act (P.L. 93-112) and to establish the right to education.

There is a tendency of groups such as those in the P&A system to resist developing high-level litigation capability because it is too expensive. Individual advocacy, however, can be even more expensive in the long run.

The allocation of legal resources will determine how effective the P&A systems will be. We must be capable of high-level litigation and allocate the necessary funds. The model of the Philadelphia Law Center may not be the best model for all P&A systems. But the other way, individual advocacy, is very costly. You must be able to show people that if they don't do what you believe is right, what you can prove by the law is right, you will have to deal with them in the forum of the courts. You must negotiate with a gun on the table.

Footnotes

[1] *Pennsylvania Association for Retarded Children* v. *Commonwealth of Pennsylvania*, 343 F. Supp. 279 (1972).

[2] *Mills* v. *Board of Education of the District of Columbia*, 348, F. Supp. 866 (1972).

[3] *Wyatt* v. *Stickney*, 344 F. Supp. 373 (1972).

[4] *Donaldson* v. *O'Connor*, 493, F. 2d 507 (1974).

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chapter 19

Securing Educational Rights for Handicapped Children

Daniel Yohalem

I have been asked to reconstruct my presentation at the two Cherry Hill workshops for inclusion in the conference's report. The bulk of my discussion was devoted to an explanation of rights under Public Law 94-142, the Education of All Handicapped Children Act, and under Section 504 of the 1973 Rehabilitation Act (P.L. 93-112), and to a detailed description of the process an individual parent would go through to secure an appropriate education for his or her child.

Rather than repeat the whole discussion here, I want to refer you to a handbook which has been published by the Children's Defense Fund entitled, "94-142 and 504: Numbers That Add Up to Educational Rights for Handicapped Children." This 52-page guide for parents and advocates fully describes who is covered by the law, what the school's obligations are, opportunities for parental involvement, procedural safeguards for parents and their children, a flow chart of the entire placement process, a chart of the major regulatory provisions, and extensive resource lists of people to contact for help in each state. A copy of this handbook was sent in March, 1978, by the Children's Defense Fund to every protection and advocacy (P&A) system in the country.*

The rest of my workshop touched briefly on my preliminary thoughts about the role protection and advocacy systems might play in implementing the educational and procedural rights contained in Public Law 94-142 and Section

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*Additional copies can be obtained from the Children's Defense Fund, 1520 New Hampshire Avenue, NW, Washington, DC 20036. Individual copies are priced at $1.75. Bulk orders of 10-19 copies carry a 10% discount; 20-99 copies, 20%, and 100 or more copies, 25%. Add 10% to all orders for mailing and handling.

504. Since the federal laws create a process and rights by which individual parents can obtain an appropriate education for their children, there is a tremendous need for well-trained advocates to work with and represent individual parents in this process. Without such advocates, critical educational rights will be ignored by school districts, parents will continue to be intimidated and confused by professional educators and their jargon, and the laws' extensive procedural safeguards will go unused. But, since most P&A systems will have relatively small staffs and have statewide responsibilities, it is likely that you will not be able to provide the day-to-day individual representation that is needed so badly throughout each state. Therefore, I think it is necessary for P&A systems to concentrate their efforts on three activities which will help this process work:

Training legal and lay advocates;

Organizing advocate involvement in state and local implementation plans;

Providing litigative, administrative and legislative advocacy on major compliance problems.

Before discussing each of these activities, I want to emphasize a crucial preparatory step that each of you should take. It is essential that each P&A advocate represent a number of individual parents from the beginning to the end of the 94-142/504 process. This is the only way for you to have firsthand knowledge of how Individual Education Plan (IEP) meetings are actually functioning in your state, whether there are sufficient experts available to work with parents, what are the difficulties inherent in your state's hearing process, and whether the administrative appeal is adequate. In my view, only with a strong firsthand knowledge of every step in this system will each P&A program be able to carry out an effective strategy to insure statewide compliance with these federal laws.

Training

Each P&A system should develop a program to train legal and lay advocates throughout the state to represent parents at each stage of the IEP/placement/hearing/appeal process. This training is necessary to multiply the impact of the P&A system throughout its state. It is important to tailor your training to the idiosyncrasies of the particular procedure in your state and to stress negotiations at the IEP meeting stage. A great deal can be accomplished *before* the school and parents become formal adversaries, and a well-prepared presentation at the IEP meeting can be very effective. There are a number of groups around the country who have trained local advocates (for example, the Massachusetts Advocacy Center in Boston), and you might want to consult with them on techniques and tactics.

Organizing Advocate Involvement in State and Local Plans

Each year, each school district in each state is required to submit to its state Department of Education a written plan spelling out precisely how it will comply with all the requirements of P.L. 94-142. In turn, each state must submit to the federal government each year a written plan specifying how it will comply with its responsibilities under P.L. 94-142. The process of developing these local and state implementation plans provides an excellent opportunity for P&A systems to organize parents and advocates to push for necessary changes in the existing system of education services and procedures. The federal regulations require that proposed plans be made extensively available to the public and that state and local agencies receive public comments on their proposed plans. In addition, there must be public hearings on the state's implementation plan. It is crucial that P&A systems use these plans to play an active role as leaders in mobilizing public pressure at the state and local levels. Public comments and hearings can also be used to focus press attention on the particular problems which you see in your state. You must recognize the political organizing needs and pressure points and build on them.

Major Problems of Systemic Non-Compliance

Each P&A system should develop the technical ability to bring class action litigation, advocate before state agencies, and develop state legislation to deal with the major compliance issues that arise in each state. In addition, you need to have good communications with community groups and advocates throughout your state to discover the major compliance problems. This way, you become an indispensable support for local advocates when they face an issue that is systemic in nature and beyond individual advocacy's ability to change. You also gain leverage with your state's Department of Education and develop the ability to cut through red tape for local advocates on their individual cases. The following problems are merely a few of the kinds of systemic issues you will have to attack: hearing officers who are school board members and thus not impartial; hearing officers whose decisions are not binding but merely advisory opinions for school boards; legislatures which fail to appropriate sufficient funds to provide educational services for all handicapped children; and school districts which, in the name of "mainstreaming," are dumping handicapped children in regular classes without sufficient special support services.

A great deal is riding on the ability of the P&A system to fulfill these three crucial roles. By linking up with legal services, organizations of parents of handicapped children, lay advocates, right-minded education professionals, Head Start programs, and other community groups, you can spread your knowledge, advocacy talent, and leadership throughout your state. At the beginning of this movement, there is so much for you to do.

chapter 20

Dealing with Zoning and Other Barriers to Deinstitutionalization

Patricia A. Siuta

Deinstitutionalization refers to the move away from large institutions, which have traditionally been segregated in out-of-the-way places, to small facilities or group homes located in residential communities, for the care and treatment of handicapped persons. Although there has been some movement away from large institutions in recent years, institutionalization of handicapped persons is still a major problem. According to Dr. David Braddock's study (1977, p. 8), 200,000 people were in retardation institutions in 1973. Of this number, 79% resided in an institution with 500 or more persons living on one campus, 60% resided in institutions with more than 1,000 residents, and 27% resided in institutions housing 2,000 or more residents.

Contrary to common belief, not only the severely handicapped are currently being institutionalized. In 1973, 25% of the institutional admissions were mildly or moderately retarded school age children. Many persons confined to institutions could live in less restrictive residential facilities within the community. In fact, in 1973, superintendents of institutions reported that over 50% of their residents could successfully live in community settings (Braddock, p. 97).

The number of residents living in institutions has been declining slowly (p. 25). To understand why deinstitutionalization is proceeding so slowly, the obstacles to deinstitutionalization must be examined. Braddock identified the following major impediments to deinstitutionalization (p. 98):

> The educational and habilitative services available to most residents of institutions are inadequate to support their successful deinstitutionalization;
>
> Closely related to this deficiency in needed services is a notable lack of individualized program planning for each resident;

> There are not presently enough community based residential services or supportive services for institutional residents or for persons at risk of institutionalization in the nation's communities;
>
> The underfinancing of community based residential and supportive services is impeding deinstitutionalization efforts in many states;
>
> Insufficient public funding is inhibiting the reform of existing institutions. Costs of renovating existing physical plants and hiring more personnel to meet accreditation requirements or court ordered quotas are often reported to be prohibitive.

Braddock's study concluded that "deinstitutionalization planning and implementation efforts should be directed toward stimulating the development of adequately financed residential *and* supportive services in community settings; and that *simultaneously*, efforts to improve the quality and variety of habilitative services available to institutionalized residents—especially transitional services—should be accelerated" (p. 48).

An additional barrier to deinstitutionalization is community opposition to the location of residential facilities or group homes in residential areas. Although many people will readily admit that community based facilities are desirable, such an admission is usually followed by the all too familiar words, "but not in my neighborhood." Property owners often fear that a residential facility will have a negative impact on the community in which it is located. Arguments frequently made against the location of a residential facility in a residential area are: (a) property values will decline; (b) there are already too many facilities in the area; (c) property is available elsewhere; (d) the children will not be safe; and, (e) the facility will interfere with the quality of life in the neighborhood, creating parking problems, traffic increase, and a decline in property maintenance (Friedlob & Anding, 1975). Methods of effectively dealing with such community opposition are beyond the scope of this discussion. Those interested in pursuing this subject are referred to Friedlob and Anding's book, citied above, and to *A Political Strategy to Combat Community Resistance to Residential Facilities* by Earl Craig Associates, Inc.

Zoning ordinances can be another barrier to deinstitutionalization. Community opposition to the location of residential facilities within residential communities can be expressed in a municipality's zoning ordinances. Zoning ordinances are laws which control how property may be used. By using their zoning powers, municipalities have been able to exclude certain groups of people from particular residential areas. This has contributed to the clustering of residential facilities in a few neighborhoods within the inner city. In order to achieve "normalization" (the rationale for deinstitutionalization) in residential services, it is essential that residential facilities be dispersed throughout the community. Normalization was defined by Nirje (1976) as "making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society" (p. 231).

Two types of zoning barriers have been used to exclude group homes and other residential facilities for handicapped persons from residential areas *(A Report,* 1973):

> Ordinances or administrative interpretations excluding group homes from some or all residential zones;
>
> Ordinances not explicitly excluding group homes from residential zones, but granting sole discretion to a zoning administrator or planning body to issue a variance or conditional use permit for any non-conforming use, thereby delegating authority to allow or prohibit group homes.

Included in ordinances of the first type are those which define "family," for the purpose of specifying what an acceptable household unit is in particular residential zones. Also included in the first category are administrative interpretations which have held that residential facilities or group homes are a business use of property, and, therefore, inappropriate for residential zones. In the second type of ordinance, the planning body has discretion in the granting of a special use permit. Special use permits for residential facilities are often denied by the administrator or planning body because of community opposition.

Strategies for challenging zoning ordinances or administrative interpretations were set forth in the July, 1973, issue of *Mental Retardation and the Law* (pp. 2-3):

> A court could be asked to invalidate an exclusionary zoning ordinance or administrative interpretations of ordinances on the grounds that:
>
> (1) the local zoning ordinance or interpretation has been expressly or implied preempted by State statute;
>
> (2) a statutory term has been incorrectly interpreted by the zoning authority so as to exclude group homes for the mentally retarded in residential areas;
>
> (3) the restrictive zoning ordinances or the pattern of denying variances under the zoning ordinance, violated Fourteenth Amendment due process and/or equal protection clauses of the Constitution; or
>
> (4) the exclusionary zoning ordinance or interpretation is beyond municipal authority.

Perhaps the most effective method of dealing with exclusionary zoning ordinances is to enact a statewide zoning statute which supports the location of residential facilities within residential areas and which supersedes local zoning ordinances. This was the approach taken in Minnesota. An amendment to the Minnesota zoning statute, drafted by the Developmental Disabilities Advocacy Project, was adopted in 1975 (Minn. Stat. §462.357 subds. 7, 8). The amendment provides that group homes or foster homes for six or fewer mentally retarded or physically handicapped persons are considered a permitted single family residential use of property for zoning purposes. Residential facilities serving seven through sixteen mentally retarded or physically handicapped persons are considered a permitted multi-family residential use of property for zoning purposes. A local zoning authority may require a conditional use or

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special use permit in order to assure proper maintentance or operation of a facility serving seven through sixteen persons, provided that the conditions imposed on the facilities are no more restrictive than those imposed on other conditional or special uses of residential property in the same zone.

In concluding the discussion of restrictions placed by zoning ordinances on the location of small community based residential facilities, it is appropriate to briefly consider another land use regulation which can result in similar restrictions—the restrictive private covenant contained in a deed or other instrument. A landowner may engage in a form of "private zoning" by placing a restriction or limitation on the use of land in the deed he conveys. A restrictive covenant may contain a restriction that the land be used for residential uses or only as a single family dwelling. In such cases the issues raised are similar to those raised in zoning cases. Two methods of challenging the enforcement of private restrictive covenants have been suggested (Chandler & Ross, 1976):

> One would be to consider all deed covenants as 'state action' and subject to constitutional review. The second would be to continue to call the covenants 'contracts', but to hold them invalid, as a violation of public policy where similar restrictions in zoning would be unconstitutional. The usefulness of either of these approaches is dependent upon a prior judicial development of constitutional restraints upon similar zoning restrictions.

These theories are also discussed in *Validity Rules Concerning Public Zoning and Private Covenants* (1966).

This discussion has been limited to identifying barriers to the deinstitutionalization of disabled persons and suggesting methods for reducing those barriers. Persons involved in deinstitutionalization efforts are referred to the cited materials for comprehensive treatment of this subject.

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chapter 21

Monitoring a Community Placement Program: The Advocacy Functions of the Willowbrook Review Panel

Jennifer L. Howse

The Willowbrook Review Panel was created in April, 1975, to monitor the implementation of a consent judgment signed in the Eastern District Federal Court requiring the New York State Department of Mental Hygiene to provide a number of entitlements, both general and specific, to members of the Willowbrook class. The Willowbrook Review Panel is a kind of advocacy system and is, for the time being at least, a one-of-a-kind system. Class members are those 5,343 persons who were on the rolls of Willowbrook Developmental Center (then Willowbrook State School) on March 17, 1972, when the class action suit was first entered. The suit had been brought by parents of Willowbrook residents as well as the New York State Association for Retarded Children and its Willowbrook chapter, the Benevolent Society for Retarded Children, after all other avenues of change for the residents of Willowbrook appeared to be closed.

On April 10, 1973, the court "entered an opinion finding that Willowbrook's residents had a Constitutional right, under the Eighth and Fourteenth Amendments, to protection from harm." The consent judgment, signed April 30, 1975, specified "steps, standards and procedures necessary to secure the Constitutional right to protection from harm for Willowbrook residents and members of the Class" (many residents had been moved between March, 1972, and April, 1975). The judgment further states that the steps, standards, and procedures are "based on the recognition that retarded persons, regardless of the degree of handicapping conditions, are capable of physical, intellectual, emotional and social growth, and upon the further recognition that a certain level of affirmative intervention and programming is necessary if that capacity for growth and development is to be preserved, and recognition prevented." The members of the class range in age from the very young to the elderly.

The Review Panel assists the department in developing plans for implementing the provisions of the consent judgment, and through periodic audits of the department's efforts, measures progress as well as making recommendations for change. The panel is oriented to the judicial process. The court itself refers to the panel as "an arm of the Court." While acting as advocate for the members of the class, the panel is not necessarily in an adversarial position with the department. Rather, on the basis of its audits and other activities, the panel supplies to the court the necessary information for the court to make various determinations. The court's orders, issued after a formal hearing, usually specify what interpretation is to be placed on a given section of the consent judgment or outline actions the department must take to accelerate its implementation.

The consent judgment directs the panel to hold an open meeting every four months for any interested person to "appear and make recommendations, comments or suggestions as to any matter within the jurisdiction of the Panel." The meetings are publicized in advance and include a report of the panel's activities since the previous meeting.

The judgment also directs the panel to file a report with the court at least every six months. These reports, as well as the periodic reports of the audits of Willowbrook, the related facilities and community placements, are available to the public. Perhaps the most important exchange of information takes place during the debriefings held after each audit with the personnel who are actually supervising the delivery of services to class members.

The panel is composed of seven members appointed by the court according to a formula outlined in the consent judgment. Two members were chosen by the defendants (the Governor of New York and the Department of Mental Hygiene); three members were chosen by the plaintiffs, and the final two members, one an expert in institutional management and the other an expert in the development of community services, were agreed upon by the plaintiffs and defendants. Two of the panel members chosen by the plaintiffs are attorneys, both of whom were closely involved with the three years of litigation, and with the development of the consent judgment itself.

The staff for the panel was limited in the judgment to three full-time professionals. It became clear early on, however, that a larger staff would be necessary to conduct effectively the monitoring and other activities of the panel. Through negotiation with the state, the panel's staff was increased to include an executive director, and four professional staff. All salaries and office expenses for the staff are paid by the state of New York.

The consent judgment is explicit in establishing the prerogatives of the panel. "Members of the Review Panel and its staff shall be allowed access to all information, records (including budget records), buildings and areas, and shall be allowed to interview any members of the Class or employee of defendants, at reasonable times and places, to the extent necessary to the discharge of their duties under the Judgment. . . . Any interference with the Review Panel, its staff, or with supervisors in connection with their duties described herein, by any person having notice of the contents of this Judgment, may be punishable as contempt of Court and subject to other sanctions provided by law."

In addition, the judgment provided that the panel might make "written recommendations to defendants of steps termed necessary to achieve or maintain compliance with the provisions" of the judgment. Such recommendations, which came to be known as formal recommendations, were to be binding upon the defendants unless within 15 business days they filed a written objection. If an objection were filed, the panel could apply to the court for an order to implement the recommendation. This process proved to be cumbersome in that the defendants did not always file an outright objection but rather sought to negotiate a resolution of the issue at hand. The panel was placed in the position of engaging in extended negotiations or going to the court to defend its already established position. The panel finally sought and received from the court an order amending the judgment to require that the defendants, when filing an objection to a formal recommendation, must also apply to the court for a hearing. The panel is also empowered by the judgment to make formal recommendations to the department.

The panel is responsible for documenting what progress the department is making in fulfilling the more than 580 requirements of the judgment. Panel staff members, therefore, spend the largest amount of their time auditing on a sample basis the Willowbrook Developmental Center with a current population of 1,600, 12 so-called related facilities administered by the department to which members of the class have been transferred, seven buildings at Willowbrook administered by United Cerebral Palsy (UCP), a 50-bed center also administered by UCP, and well over 500 community placements throughout the state. At the outset, when the degree of compliance with the judgment was minimal, the audit instrument used by the panel staff was relatively simple and focused on the basic environment, living standards, and programmatic requirements. As could be expected, the panel and the Department of Mental Hygiene did not always agree on the accuracy of the audit findings. Through lengthy negotiations, the panel and the department have agreed to a comprehensive audit instrument embodying all of the standards set forth in the judgment, a much more sophisticated document in which the requirements of the judgment are grouped together as they apply to the various aspects of a class member's life. The audits are conducted by the four program associates on the panel staff in conjunction with four representatives from the department trained by the panel staff. The measurement of compliance with the judgment is only part of the audit function. Prior to the publication of a report of the audit findings, the staff of the facilities and programs, (including staff of voluntary providing agencies in the case of community placements), are debriefed as to the audit findings in order to reach consensus on the data base, and to determine courses of corrective action. The final audit reports include recommendations for change, and the audit thereby becomes a positive instrument for progress.

Complaints and inquiries regarding individual class members are also investigated by the panel. They range from alleged abuse to inadequate program services and lack of personnel. The panel pursues both the amelioration of the specific situation and the possibility of a systemic failure which may have prompted the complaint or inquiry. While it prefers a written presentation, the panel investigates each situation reported to it by letter, telephone, or in person and documents resolution when it is achieved by letter to the complainant or inquirer.

Both the audit and the complaint and inquiry processes can and have led to the issuance by the panel of formal recommendations to the department. The panel, however, has always attempted to resolve any issue of conflict prior to issuing a formal recommendation. Of twenty-one formal recommendations made to the department, six were rejected, requiring either a court hearing or extended negotiation to achieve resolution. Five recommendations were accepted, although they were issued subsequent to discussion of the issues and served largely as the catalyst to resolution. Six formal recommendations were accepted in part, with their specific implementation most often the point at issue. Three recommendations were resolved through a memorandum of understanding approved by the court, and one was withdrawn by the panel when the department proposed an acceptable alternative.

Although the panel has sought to apply to the court only as a last resort, court hearings have generally reinforced the panel's position even when the ultimate ruling by the court did not totally uphold the panel's specific recommendation or interpretation of the judgment. A hearing, however, requires the preparation of court papers, the accumulation of evidence regarding the issue involved, and the presentation of witnesses; it may take only a few hours or several days. In the panel's experience, the court's ruling on the matter will be issued two weeks to a month following the hearing. When the plaintiffs moved for a contempt citation against the defendants for failure to implement the judgment, the panel, although it was not directly involved in the motion, had supplied through its audit reports the information on which the charge of contempt was based.

The subsequent "Stipulation and Order of Consent" issued by the court included 28 conditions, agreed to by the plaintiffs and the defendants, which the department would meet to avoid contempt.

Although the audits of the department's efforts at compliance have become increasingly sophisticated and comprehensive, there is greater acceptance by the department of the audit findings and the recommendations based on those findings. The audit results can indicate improvement; for example, in the most recent audit of the so-called related facilities, a significant increase in the hours of programming provided to class members was reported. Perhaps the most significant indication of success is that the panel has not had to apply to the court for rulings on its recommendations as often as in the past. At this point, negotiations between the panel and the department focus less on what must be done to fulfill the mandate of the judgment than on how and when it will be accomplished.

The overall objective of the consent judgment is the provision to the members of the class, required services in the least restrictive environment. This provision must include an upgrading of services at the institutions, Willowbrook and others, where members of the class still reside. It must include the reduction of the population at Willowbrook by April 30, 1981, to 250 or fewer beds to serve the geographic area of Staten Island, and it must include the placement in the community of a still undetermined number of class members.

Section V of the order, *Community Placement,* in addition to requiring the Department of Mental Hygiene to reduce the population of Willowbrook and to develop facilities and programs to serve class members in the community, also mandates that the Review Panel, in collaboration with the Department of Mental Hygiene, prepare and recommend "a detailed and comprehensive plan for the development and operation of additional community facilities and programs to meet the needs of Willowbrook's residents and of the Class." It is this provision of the judgment which will ultimately bring about the greatest change in the delivery of services to developmentally disabled persons in the state of New York.

Section V defines a community placement as a "non-institutional residence in the community in a hostel, halfway house, group home, foster care home, or similar residential facility of fifteen or fewer beds for mildly retarded adults, and ten or fewer beds for all others, coupled with a program element adequate to meet the residents' individual needs." The community placement plan further specifies the comprehensive services (medical, dental, psychological, educational, vocational, therapeutic, etc.) needed to support a community placement program.

To initiate its placement program, the department established in early 1976 a Metropolitan Placement Unit. Its function is to develop the necessary residences and programmatic and other support services for class members. The Community Placement Plan prepared by the panel, calls for the establishment of a developmental services office in each of the five boroughs of New York City. The borough developmental services offices, as they are established, will assume, on a permanent basis, the functions of the Metropolitan Placement Unit and will continue to develop and maintain a community based service system. In the first year after the signing of the consent judgment, the department was to develop 200 new community placements. Slightly less than 150 class members were actually placed by April 30, 1976. Now more than 500 placements have been made and in its audits the panel has found them to be of good quality. The majority of class members, however, are still to be placed.

The panel, as a unique entity, has had to develop its own procedures, methods, and instruments for fulfilling its mandate under the consent judgment. Although the staff works full time, the panel itself meets once a month, or more often if special issues need to be resolved. It may be a measure of success that special meetings have been less frequent in the past year.

Since the panel was unique and could not model itself directly after any other advocacy system, it was helpful at the outset to ask some fundamental questions about how panel operations should be developed and maintained. Asking these questions helped to focus our aims; the questions continue to guide us.

1. What is the mission of the Review Panel? For what purpose does it exist? What are its possibilities and limitations?
2. What is the system trying to accomplish? That is, within the overall mission, what are the specific end results the panel will be expected to achieve?
3. What resources are available?
4. What are the legal and administrative prerogatives of the panel?
5. What strategies must the panel develop in order to accomplish the various tasks dictated by its mission?
6. How does the panel evaluate its successes and failures? Should its concerns be systemic or individual? Is the reliability of the compliance data produced acceptable to having a stake in its reliability?

The most lasting effect of the consent judgment and the activities of the Review Panel is likely to be the implementation, by the department, of the community placement plan. The objective of the plan is to develop a community oriented service delivery system and to move the residential institution from its present position as the hub of the service system. The effective implementation of the Community Placement Plan has been, and continues to be, the first priority of the panel, since only through its accomplishments will the provision to class members of the entitlements of the consent judgment be finally guaranteed.

Changing an entrenched institutional system is never easy. The mandate of the consent judgment that members of the class be placed in the community dictates a major change for the Department of Mental Hygiene. The process of change must be evolutionary and is inevitably slow. In its two and a half years of operation, the panel has seen considerable change—some of it, unfortunately, meaningless exercises, but much of it focused and producing results. Because the primary thrust of the consent judgment is to provide the least restrictive environment for class members, the final measure of success will be the placement of these clients in the community, with an effective system of support services to allow them to live as freely and productively as possible.

chapter 22

Reaching Out to Serve the Minority Developmentally Disabled Citizen

Naomi T. Gray

The organization, New Dimensions in Community Service, Inc. (NDCS), is nonprofit and was established for the specific purpose of creating and implementing relevant services and programs for minority groups. Its primary goals are to foster participation and solutions to problems affecting health, education, and economic and social well-being of the individual and family through programs of self-help, self-determination and community awareness. The organization sponsors summer recreational programs for school-age children of working parents, conducts public education programs relating to health, social, and education issues, and provides consultation and other related human service activities to community based groups and organizations. Members of the board of directors are active in the life of their communities. Their experience is multidisciplinary, and all are minority group members. The consultants and advisors are also minority group members, and their disciplines include social work, public health, education, psychology, psychiatry, dentistry, child care, sociology, program development, and management. Some are consumers.

New Dimensions in Community Service, Inc., is currently implementing a nationwide study on the quality and quantity of minority participation in the developmental disability movement. The project is funded by the Office of Human Development, Developmental Disabilities Office, Department of Health, Education, and Welfare. Since the majority of the population is not familiar with the term *developmental disabilities* and its specific connotations, it can be concluded that black and other minority populations have little or no knowledge of developmental disabilities, and consequently are not involved in program development and policymaking, nor have they been recipients of services. In addition to implementing the nationwide study, our organization recently concluded a project to educate San Francisco's black community about developmental disabilities (DD). This one-year project was funded by the California State Health Department, Office of Developmental Disabilities. A community education program and needs assessment for the developmentally disabled preschool black child and infant were part of this program.

An important part of any community education process is an assessment of community needs in the area of developmental disabilities. Needs were assessed from two points of view: (a) that of the parents of disabled children, and (b) that of agency personnel who worked in hospitals, clinics, social services, and DD provider agenices. In order to effectively conduct outreach and case finding programs, it is necessary to know the community where the program is conducted. It is important from the beginning to become familiar with the various public and private developmental disabilities service systems. In our Black Child Project, our staff shared reports of individual observations and data in such forms as brochures, fact sheets, and referral and resource directories. Information collected in this fashion was organized into our own major directory of resources and formed the basis of our referral network. This network grew in strength as our community outreach expanded.

As the project progressed, we were able to assess needs and set priorities. The needs were primarily categorized as personal, family, and socioeconomic needs. The socioeconomic needs were identified as those needs which were made known to us by the majority of contacted individuals and agencies involved in developmental disabilities. These were counseling, transportation, respite or child care, infant stimulation, and the education of parents, physicians, dentists, and other professionals. In many cases, parents brought up basic survival needs, such as food, clothing, and shelter, before responding to the subject of developmental disabilities. Special child care and transportation were most often mentioned.

The main tool of our education and awareness campaign was the Black Child Developmental Disability Project brochure. This brochure was distributed broadly to more than 300 agenices and to more than 5,000 people by our three staff members. (The project had a full-time director and two part-time outreach workers who were parents of children with developmental disabilities.) For example, the San Francisco Department of Social Services requested and was supplied with 2,000 brochures for distribution to its clientele. In addition, we were able to distribute our brochures through food stamp and food supplement outlets. Public service announcements were sent to four of the major television stations and to black-oriented radio stations. This generated numerous telephone inquiries. The black newspaper provided coverage of our project with a number of feature articles and news stories.

Our outreach activities uncovered 180 cases of children with emotional and mental handicaps, learning disabilities, Down's Syndrome, epilepsy, and autism. Of the more than 300 contacts we made, approximately 50% were referred to medical/health care resources for diagnostic purposes. Referrals (45) were made to health and welfare agencies because of special needs of individuals falling outside the project's purposes.

The following recommendations resulted from information received from personal contacts during the 12 months duration of the project. These are based on the project staff's assessment of the needs that exist for serving the black child who is developmentally disabled:

- Inclusion of consumers in decision-making processes;
- Community education on developmental disabilities for prevention and awareness;
- Parent education on working with their children;
- Sensitization of agency personnel to the needs and differences of members of various ethnic groups in an attempt to better serve;
- Education of public school classroom teachers;
- Respite and child care facilities;
- Transportation to and from provider agencies;
- Individual and family counseling and referral.

Our project concluded that the black and other ethnic minority communities would benefit more directly from their own neighborhood developmental disabilities center before successful "mainstreaming" can take place. Such a community based facility will expedite the use of existing services in the general community. It could also serve as an observation point for white professionals as part of specialized training on how to work with minority clients.

It is essential that the service provider in developmental disabilities fully understand the social-medical needs of its target community and find the right approach for reaching people. It is necessary to establish rapport and communication among the providers and the potential consumer groups. In reaching out to the community, particularly the minority disadvantaged, a comprehensive approach should be stressed. Other types of health education and information should also be imparted. The community educator should work very closely in cooperation with other community agencies, organizations, and institutions to insure a coordinated and unified approach to education about developmental disabilities in the minority community. Agency personnel expressed concern for lack of client follow-up on medical appointments, transportation and staff training on how to work with the various ethnic/cultural groups.

A paper published by myself and Russell Richardson in 1968, entitled "Community Organization, Strategies and Techniques for the Provision of Family

Planning Services," discussed how outreach programs can be effective. We stated that among other approaches:

> The outreach worker should be equipped with knowledge about other community resources where individuals may be referred. Through the years a variety of interventive approaches have proved effective in influencing change in political, health, welfare, and educational institutions towards the delivery of family planning services. Among these techniques, which appear in blends and mixes in these practical illustrations, are: Outreach; formation of grass roots citizen groups; coalitions and alliances with the groups' common interest; educational measures; and influencing social legislation. Outreach includes informational contacts with low income families in their own neighborhoods, meeting in housing projects, lectures in community centers, rap sessions with teens, involvement of males, etc. Formation of grass roots groups to work for development and expansion follows and is dependent on consistent outreach. This development of an informal communication network is essential and relies on the ability to meet and work with low income families in their own environment in order to engage their participation.

For the community at large, the DD agency should make known the type of services offered, to whom the services are offered, at what cost, and the eligibility requirements. The agency should also clearly state its goals and objectives. The use of mass media—radio, television, magazines, and newspapers—is a traditional means of conducting information programs. It is extremely important that this type of public information be carried on consistently so that the community will know exactly what services the agency offers and for what purposes.

The use of bilingual materials and community educators is essential for carrying the DD message to minority populations. With the diversity of racial/ethnic people in many communities, DD providers should have knowledge of the bilingual and bicultural needs in each community if programs are to succeed.

On the basis of its experience, New Dimensions in Community Service, Inc., can make the following recommendations to agencies wishing to reach out to minority clients:

1. Assess your readiness to do outreach and to relate to minority clients. The agency must look at agency structure, as well as at staff attitudes and other such subtle things that parents and others notice when they come to the agency.
2. Develop goals and objectives for the outreach program. These goals affect the method of outreach. They may include: identifying clients for referral for services offered by other agencies; locating potential clients for the agency doing the outreach; distributing information about the agency or disabilities; increasing community awareness about disabilities; and acquainting the agency and its staff with the needs of the minority community.
3. Assess what outreach tools or approaches will work best in the minority community. This necessitates some prior knowledge of training and understanding of the minority community. The agency could achieve this knowledge and understanding by having minorities on the staff and by ongoing

in-service training for non-minority staff. In assessing which methods work best in minority communities, the agency may consider: health fairs; leaflet distributions; parent groups; radio or TV spots; posters; home visits; visits to other agencies; circulating mobile units/clinics; community meetings; contacts with institutions within the minority community such as churches, professional associations, social clubs, and using minority consumers as outreach staff.

4. Use barometers to assess the effectiveness of outreach in the minority community. For example, the agency may randomly call agencies within the community to see if they know about the agency's program. Some measurements of successful outreach are: number of new minority clients identified; increase of reported incidents of disabilities among minorities; increase in caseload; increase in requests for informational material; identification of previously unknown informational materials for minorities; requests for the agency's participation in community meetings, health fairs, orientation of other agency staff; increase in telephone inquiries from minorities; increase in referrals from other agencies; requests for minorities who are involved in working with developmentally disabled persons to serve on advisory boards, commissions, committees and so forth; organization of a grass roots advisory committee to the outreach program; and recruitment of minority volunteers.

In summary, serving the minority DD person encompasses a broad range of programs and services including the involvement of minorities in the agency's program planning and implementation and as policy/decision makers on boards and committees. People who live in the community are more effective representatives of minority interests than those who do not. Minorities must be allowed to become advocates for themselves within the existing system.

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Part Five

Resource Organizations

chapter 23

Relating To The National Advisory Council

V. Max Arrell
Claudia Dickson

This discussion addresses the following questions:

- What is the National Advisory Council (NAC)?
- Who are its members?
- What is the purpose?
- What does it do regarding protection and advocacy (P&A)?

The following remarks represent the opinions of the authors and not necessarily the NAC as a whole, since the NAC is composed of individuals who have their own ideas and opinions about what the NAC should be doing as a group. The senior author is a member of the NAC.

Historical Context

The NAC—whose full title is the National Advisory Council on Services and Facilities for the Developmentally Disabled—was first authorized by The Developmental Disabilities (DD) Act (Public Law 91-517), on October 30, 1970. Antecedent legislation contained no such provisions, although state level advisory councils were provided for in Title I of P.L. 88-164 relative to the construction of mental retardation facilities.

The DD Act of 1970 specified July 1, 1971, for the establishment of the National Advisory Council, and the Secretary of the Department of Health, Education, and Welfare (HEW) issued an order establishing the council. However, no members were appointed until October of that year and their first meeting was held in January, 1972. Section 133 of the Act called for 20 members appointed for four-year staggered terms and established the functions of the NAC. Dr. Elizabeth Boggs, who was among those appointed to serve, was designated chairman.

The functions of the NAC established in Section 133 also were set forth in the original charter granted to the council. These functions were to advise the secretary on regulations and to determine the effectiveness of the program authorized in accomplishing the purposes of the Act.

In addition, in 1972, Elliot Richardson, then Secretary of HEW, asked the council for advice on extension of the DD legislation.

The NAC Today

The 1975 DD legislation (P.L. 94-103) established a different composition of membership, now requiring 25 members, including 16 nonfederal members appointed by the Secretary of HEW and nine ex-officio members who are HEW officials. The six of these appointed by the Act are:

Deputy Commissioner of the Bureau of Education for the Handicapped;
Commissioner of the Rehabilitation Services Administration;
Administrator of the Social and Rehabilitation Service (SRS);
Director of the National Institute of Child Health and Human Development;
Director of the National Institute of Mental Health;
Director of the National Institute of Neurological Disease and Stroke.

These potential members of the NAC may be nominated in a variety of ways. The Developmental Disabilities Office makes recommendations for potential members, and the secretary's office also gets nominations from congressional offices, state agencies, public interest groups, governors, the White House, and any other interested individuals. Presently, there are seven vacancies on the NAC, five created by the completion of four-year terms, and two by resignations.

Since the SRS was abolished as part of the reorganization of HEW, Title XIX (Medicaid) was transferred to the newly created division of Health Care Financing Administration, and their director has been represented (unofficially) on the NAC.

The 16 nonfederal members must include five representatives of state, local, public, or nonprofit agencies and five persons with developmental disabilities. A qualifying characteristic is that they are advocates in the field of developmental disabilities, coming, for example, from consumer advocacy organizations, higher education institutions, or state or local government.

General Functions

The NAC meets at least twice a year but usually more frequently than that. Its five working groups meet even more often. They include: executive, grants review (including special projects and university affiliated programs), evaluation (including advocacy), program monitoring (state formula grants), and regulations.

The current DD legislation (P.L. 94-103) broadened the responsibilities of the NAC, providing for specific monitoring activities and input into Secretarial decision-making. These broadened responsibilities are:

> To evaluate the efficiency of the administration of the DD program and to report to Congress;
>
> To review grants authorized by P.L. 94-103—including projects of national significance, special projects, the evaluation system, and federal standards applicable to residential facilities and community agencies—and to advise the secretary;
>
> To study, evaluate, and monitor development and execution of the DD program and report to the secretary.

The second function, in the opinions of the authors, merits further comment. Reviewing grants is an important aspect of the NAC; however, it also can be a hindrance. Because it involves dealing with money and making specific decisions as to who will and who will not get money, it is a situation laden with emotion. Sometimes an inordinate amount of time is spent in this process. In the opinion of the authors, the NAC's focus should be directed toward the overall DD program without unduly emphasizing this segment of it.

One area of focus for the NAC this year has been trying to get as much input as possible from consumer organizations. A tremendous amount of time has been spent by the NAC in listening to people who serve the developmentally disabled clientele. This, the authors feel, is one of the most important functions of the NAC. It is crucial for people around the country to make an effort to get to know the NAC members in their area and let them know what the individuals working in the DD field on a daily basis would like to see in the DD movement. The NAC makes a report to Congress each year, and the report contains recommendations which can only come from the grass roots level.

NAC Functions Regarding P&A

The mandated roles and responsibilities of the NAC represent an advocacy posture that is vital to its functioning as an advisory body. In fact, the NAC has considered substituting the term *advocacy* for the word *advisory* in its title.

Inherent in its advocacy posture is the idea that the NAC is not only a responsive body, but also an action-oriented group. In many ways its philosophy is similar to that of systems advocacy organizations: Both aim to influence social and political systems to bring about change for groups of people. Systems advocacy can mean changing laws, regulations, service delivery systems, or customs for the purpose of creating a favorable climate for the development of services for disabled persons. Systems advocacy approaches commonly used by the NAC include initiating, influencing, and monitoring legislation, rules, and regulations affecting developmentally disabled persons, and initiating, influencing, and assisting in the development of new services, and improving and expanding existing services (such as projects of national significance).

Charge to New Advocates

Advocacy represents a new addition to service delivery systems for developmentally disabled persons. It has, potentially, a profound impact on the implementation of legislative decrees and the range and structure of community programs. Those implementing the P&A systems must approach their jobs mindful that advocacy per se precedes the establishment of the P&A systems and their interest and involvement in the systems. They have an opportunity to establish new attitudes and a new climate for services. They must look beyond and be perceptive about what they are doing today for a client, for they are really laying a foundation for a lifestyle of tomorrow for that individual.

We have sensed an intensity among the P&A people. They want ideas and answers that they can use in doing their jobs. That intensity can be good if it is used and channelled appropriately. In concluding this chapter, we would like to offer several suggestions and cautions for channelling that intensity and energy.

Find the "Ohs." The senior author of this chapter is always somewhat concerned about being introduced to a group of advocates as being deputy commissioner of a state vocational rehabilitation agency because their typical response is, "Oh." We think advocates need to realize that there are some "ohs" around who are interested in developmentally disabled people.

In Chapter 2 of this volume, Fran Lynch describes the meager resources available for the P&A program. Nationally, the program has $3 million, with $20,000 in several states, and as much as $200,000 in a few states. Even if the entire $3 million were put into Texas alone, for example, the P&A people still could not do the job that they are mandated to do. Some people feel that advocacy cannot take place within the system but that it has to be from the outside. I am convinced that effective advocacy can occur either inside or outside of the system. With resources this limited in scope, P&A personnel are going to have to dig to find as many additional resources as possible, including all the "ohs" in their state. Find the people who are interested, and there are some. Don't condemn all people in the service delivery system. Some of them are very interested in the same kinds of things that advocates are interested in, and they can help carry the advocates' banner.

But remember that service delivery people also have pressures from other places and have to live within the bureaucracy. There is a process in the bureaucracy known as "dynamic inactivism." It works in the following way. When advocates approach bureaucrats, the advocates are a bit suspect in the first place because the word *advocacy* may frighten the bureaucrats. And even if the bureaucrats greet the advocates with open arms, the bureaucrats may not necessarily agree and cooperate with the advocates. Frequently, there seems to be a flurry of activity in an agency: Everyone is moving; everyone has things going. The advocates arrive; the bureaucrats assemble their staff, and everyone sits down to discuss what the advocates want.

The advocates may wish to explore and monitor some of the things the agency is doing. The bureaucrats may give all the right answers: They may offer to give the advocates all kinds of information from the computer and offer to make the staff accessible to them. But then after the advocates leave, the bureaucrats may write the advocates a letter saying, "Although I want to give you this information, because of the Privacy Act, I'm not sure I can give it to you. Therefore, I'm writing for the attorney general's opinion." Many months may pass before the attorney general issues an opinion; meanwhile, nothing happens. This is dynamic inactivism. On the surface, the bureaucrats appear to be doing everything they can to work with the advocates, but in fact, they are setting up barriers. That's the hardest thing to fight in the advocacy program. If the bureaucrats would come out and fight the advocates, then the advocates could deal with it. But that's not the way the bureaucracy works. Dynamic inactivism—everyone is working, moving, cooperating, but nothing's getting done. Six months later, no progress has been made. Hence, the point remains: P&A personnel must find the "ohs" in that agency. They are there, and they can help.

Make the P&A systems visible. Unless the public and those who are in need of advocacy services know about the P&A systems, what they can do, and how to access them, the systems will not get off the ground. Advocates need to use proven techniques to enhance communication and the public education process.

Make the P&A systems responsive. By listening, P&A personnel can truly become action-oriented advocates. Many individuals and groups will offer advice, including state agencies, state councils, consumers, and lawyers. Advocates should listen to this advice, yet bear in mind that a considerable gap exists between philosophical ideals and the establishment of a successful protection and advocacy system. Each advocate group must work within the constraints of its own state.

Be careful. The P&A systems need to make a mark in the next 10 or 12 months. They need to make some progress so they can then say, "This is a great and worthy task. It needs to be continued, and we need more funds." The advocacy programs cannot be self-serving; they must serve the people they are designed to serve. Short-range goals are important, but advocates also must consider the long-range effects of what they are advocating and what it will mean to the developmental disabilities movement 5 or 10 years hence. In short, advocates must be careful what they ask for; they might get it, and they will be held responsible.

chapter 24

Interacting With The National Conference On Developmental Disabilities

James MacDonald Watson

A host of presenters has already cautioned you, counseled prudence, explained the enormity of the job of protection and advocacy (P&A) and the poverty of its funding, and painted a rather solitary and probably thankless task. There is some reason to take heart, however, and P&A people can learn from the survival skills acquired by state councils on developmental disabilities. The history of the developmental disabilities (DD) movement is brief, comprising only seven years. As an aside, I have to confess that I am a physician, a neurologist, and did not know that the term *medical model* was pejorative and even impolite until I had been dragged unwittingly into DD-land as a state council member six years ago. "Dragged" is not an imprecise word, for many of us in those days were swept up in an activity about which most were ignorant, but earnest.

This leads me to a point I would like to make about state councils. Many council members, if not all, were and are earnest and sincere, though often possessed of a vested interest they did not really know they had. Few members, however, were, or now are, completely informed about overall national and state objectives and projections for the future. State council members serve in varying terms at the convenience of a governor's appointment, and governors serve at the will of the electorate. This means that often all a council member has going for himself or herself is good intention, because longevity is hard to come by in such a system, and without longevity, sophistication will be lacking. This we will call the "good news."

The "bad news" so to speak, without offense, if possible, is that the bureaucracy with which the councils deal does not really change at other than a snail's pace.

Hence there is no necessary guarantee that the state agency which administers a state council plan has either the intent, willingness, or statutory responsibility to behave in any way resembling the good-hearted, if naive, intention of the council's plan. The confrontation of a relatively untutored council and a well-entrenched bureaucracy, whether federal, regional, or local, is heavily weighted in favor of the latter or, at least, forecasts very hesitant forward movement.

However, in these seven years, remarkable progress, not at all uniform and not at all to the liking of our more severe critics, has occurred. The organization of the state councils, the National Conference on Developmental Disabilities (NCDD), has been instrumental in achieving some of it. Presently some 75% of the councils are actively participating. The organization has been developing over the past six years in large part because of the insights of a few strong council people who realized that a multi-state, multi-regional situation existed which the legislation did not address and that a coherent and unified approach from the councils to various problems was required. NCDD is non-statutory (unlike the National Advisory Council) and is composed of three delegates from each state. It has had at least one if not two national meetings yearly since its inception, and with the guidance of a thoughtfully chosen executive committee has produced effective contributions in regulation development and clarification, renewal legislation, minimally-funded states' problems, and coordination of an overwhelming wealth of technical assistance for state councils. The executive committee has also maintained a very close liaison with the National Advisory Council in its separate activities. We have also represented the state councils as members of the Task Force on Definition of Developmental Disabilities and on the advisory council of the project of national significance known as "Federal Programs Information and Assistance Project." The present mission for the conference is to shepherd closely the new legislation that must develop by October 1, 1978, to be followed by a look at evaluation techniques at a winter meeting.

NCDD is supported entirely by its individual councils on a voluntary basis, but recently incorporated in the District of Columbia, thereby allowing it to solicit grants and contracts for specific functions. It scrupulously avoids using state council money in lobbying. It is attempting to establish a formal membership protocol with prorated levies to each council.

The planning councils are a new phenomenon in relative terms. Advocates are very new and therefore somewhat more vulnerable, and yet perhaps somewhat more secure. The council system in state after state is just imperfect enough that a good P&A system enforced by federal statute could replace the existing council system. The P&A system could, however, just as easily become the patsy of either the federal or the state system, as has been the case of some councils.

The road to general, if not universal, acceptance and success is neither easy nor perhaps even attainable, and is slower than one can conceive. I urge you as you become more aware of your own roles, more aware of your relationship with state and federal policies and guidelines and politics, to consider and develop a common thread of purpose and intent—even liaison—with our group, because our goals and missions are the same.

NCDD has been said to represent only a set of vested self-interests, principally councils who have been impotent. That is not true, and we intend to prove it. You are beginners in the effort to utilize the federal and state mandates. I entreat you to join us in our effort to expand and stabilize the concept of "DD." Your first "client" in DD advocacy might very well be the system itself.

The rules change, the protagonists waiver, the spirits flag, but the purpose and need remain.

chapter 25

National Center for Law and the Handicapped: In The Forefront Of Advocacy For Disabled Persons

Jean Postlewaite

For five years, NCLH—the National Center for Law and the Handicapped—has worked to insure the rights of handicapped citizens. The idea for a national center resulted from an incident where a slightly retarded child was denied admission to the public school system and a simple phone call from an attorney resulted in the child's placement. The incident illustrated how an attorney could be of great value in dealing with such cases, for at that time, few attorneys, either in private practice or in the public sector, were adequately prepared to litigate cases or to provide legal counsel to mentally or physically handicapped individuals deprived of their civil rights. Moreover, the pervasiveness of the deprivation, which was not limited to a particular geographical area, supported the concept of a national center.

Consequently, in 1972, the University of Notre Dame Law School and the Council for the Retarded, St. Joseph County, began to formulate plans to establish a national legal advocacy organization, a unique and innovative concept. The two organizations, with support from the National Association for Retarded Citizens and the Family Law Section of the American Bar Association, applied for federal funding. Since its inception, joint funding of the center has come from the Department of Health, Education, and Welfare's Bureau of Education for the Handicapped and the Developmental Disabilities Office.

Currently, NCLH has an interdisciplinary team of attorneys and social science professionals working together for the establishment and implementation of the legal rights of disabled persons. The activities of the entire staff of approximately 15 professionals, whether direct legal intervention, legal assistance, conferences, publication, or general information, center around such key issues as the right to education, to treatment and community based services, to equal employment opportunity, and of access to transportation and the built environment. The need for specialization in these areas has greatly increased over the years, particularly as a result of major federal legislation and an expanding number of test cases.

Although the center has served in court cases in the capacity of counsel and co-counsel, it primarily becomes involved in the role of a friend of the court *(amicus curiae)*. The staff consults regularly with attorneys, organizations and other individuals concerning potential litigation and changes which can be made in state and federal legislation. NCLH has interceded in behalf of hundreds of individuals discriminated against because of their handicaps and has successfully resolved their complaints, often with a simple letter or phone call, using litigation in the courts as a last resort.

Special efforts are made by the center to provide comments to federal agencies issuing regulations to implement laws affecting handicapped persons and to assist legislators and professional and consumer organizations in drafting and reviewing model legislation. Representative Robert Kastenmeier of Wisconsin, for example, requested NCLH comments regarding proposed legislation to authorize the U.S. Justice Department to bring suits in behalf of institutionalized persons. NCLH comments were submitted to the Department of Health, Education, and Welfare regarding proposed regulations to implement Section 504 of the Rehabilitation Act of 1973 by the executive branch of the federal government and regulations to implement Public Law 94-142, the Education for All Handicapped Children Act.

Training Programs

A legal internship program was established in the first year of NCLH operation as a curricular project with the Notre Dame Law School, for years a leader in civil rights advocacy. Second- and third-year students are given the opportunity to work in the area of civil rights for the handicapped and perform much of the research which goes into the work of the center. The law school also offers one of the few courses in the country on law and the handicapped, which is coordinated by the center and open to all law students.

An intern outreach program was initiated last year to bring law students from other colleges and universities to the center, as well as to place current interns in off-site programs and legal advocacy offices across the country. An NCLH intern was placed with Project Impact, a regional advocacy office of the National Association for Retarded Citizens, located in Burlingame, California. The intern visited various minority groups, identifying their problems and assisting staff members in locating appropriate resources for dealing with those problems. A law student "extern" from Northeastern University in Boston spent a term with the center. The individual is now working with the Metropolitan Human Rights Commission in Fort Wayne, Indiana, and has filed a class action suit against the Fort Wayne community schools' special education program, charging inadequate placement of pupils. NCLH also began in 1977 a training program for new attorneys. Attorneys from Washington state, Washington, DC, and Vermont received training at the center and are now actively involved with discrimination cases.

Public Education Programs

Heightening the awareness of professionals to the problems of the disabled, as well as providing information to disabled consumers about their legal rights, have also been major objectives of the NCLH program. The center has been responsible for conducting a number of national workshops and conferences focusing upon such key issues as education, medical care and treatment, accessible transportation, and equal employment opportunities. Plans are now underway to hold a symposium on the employment rights of the handicapped in April sponsored jointly with the DePaul University School of Law. NCLH will also assist the Notre Dame Law School in the publication of their spring issue of the *Law Review*, which will deal exclusively with rights to employment.

NCLH staff members are frequently requested to address groups and hold seminars and training sessions for both professionals and nonprofessionals who are anxious to increase their knowledge of the rights of the handicapped.

Although *Amicus* is the center's primary vehicle for public education regarding the rights of the disabled, legal monographs prepared by the NCLH staff, as well as materials prepared by other organizations or individuals, are disseminated in response to requests for general information. Hundreds of requests for more specific information receive individual attention every month.

A few of the major publications projects presently underway at NCLH include a book under contract with the American Civil Liberties Union on the rights of physically handicapped persons; a series of "how-to" manuals for use by judges in civil commitment hearings; and a directory of attorneys actively involved in litigation in behalf of handicapped persons.

The NCLH library contains invaluable resource material of great benefit to the NCLH staff and to those requesting assistance. Particularly noteworthy are the files of both reported and unreported cases, which are frequently difficult to obtain. Copies of these cases are available from NCLH.

A Resource to the P&A Systems

The resources of NCLH can be of great value to those working within the state protection and advocacy systems. Legal assistance from staff attorneys may

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be rendered on a wide range of possibilities, from litigation strategy to comments on proposed legislation.

Copies of case materials are distributed free of charge; in fact, all materials disseminated from the center currently have no charge.

The training of lay advocates and paralegals is a common concern among the P&A systems. In order to adequately protect the rights of each state's population of developmentally disabled individuals, more than a few staff attorneys will be required. Assistance in the development and delivery of training sessions is a common activity of NCLH staff, as are the frequent presentations made to various groups throughout the country regarding the rights of the handicapped.

Finally, through its programs of public education, NCLH can serve the P&A systems by providing a network of communication. News of available resources, new litigation, legislation, programs, and so forth, may all be relayed on a nationwide scale through publication in *Amicus* and through responses from the NCLH information specialist to incoming inquiries.

In order to perform these programs of assistance well, however, NCLH must be kept informed of new developments within each state, including new legislation, new cases filed and decisions reached, new programs, and new materials developed.

The expertise that NCLH has developed during its existence has benefited individuals in every state of the country. The feeling in 1972 of the need for such a center was an accurate assessment, judging from the development in only five years of major legislation and litigation which has the capability of substantially improving the lives of the thousands of mentally and physically handicapped persons in our country.

Part Six

Outlook

chapter 26

Using Your Uncommon Sense

Leonard W. Mayo

You may have heard of the man who thought he knew so much about the subject under discussion at a conference he attended that he was contemptuous of those who were ready and willing to inform him. He soon found, however, that he had a great deal to learn, and his contempt turned to humility. He said later in speaking of the experience, "I came to scoff and I remained to pray."

I assure you I did not come to this meeting to scoff, but I was not aware of how much there was to learn; I am grateful to you and to the leaders and sponsors of this conference on protection and advocacy for a very liberal education during the last four days.

In your behalf as well as in my own, I would like to express appreciation to the federal Developmental Disabilities Office, to the Research and Training Center in Mental Retardation at Texas Tech University, and to the New Jersey Department of the Public Advocate for their sponsorship and support. And I am sure you wish me to acknowledge with appreciation the very able leadership of Jerry Bensberg and Linda Baucom in the planning, coordination, and conduct of these meetings. Finally, our thanks to the Cherry Hill Hyatt House for its hospitality and cooperation.

I have been impressed these days by the extraordinary dedication and sincerity of those of you who are preparing for this highly important and sensitive type of human service. I hope you will enter into it not only with a great deal of common sense, but with a good measure of *uncommon sense* as well; by that I mean, quite specifically, a sense of *history*, a sense of *relatedness*, a sense of *mission* and, last but not least, a sense of *humor*. I would like to say a few words about each of these.

A Sense of History

It is well to remember that you are not the first to undertake the task of helping people to realize the promises of democracy. A great company of men and women have preceded you; not a few of them were giants in their time and still stand as exemplary models of advocacy at its best.

Florence Kelley and Owen Lovejoy were advocates for the children who, at the turn of the century, were working long hours under horrendous conditions in factories and on farms. Julia Lathrop and Grace Abbot became advocates for all the children of the land when they insisted that a nation that had a department of agriculture devoted to improved methods of raising hogs and cattle could afford a division of government dedicated to the care and nurture of children. Together and with a small group of fellow advocates, they persisted until the President of the United States concurred, and The Children's Bureau became a reality. Clifford Beers, himself a patient in mental hospitals, was an articulate and vigorous advocate for the mentally ill, exposing the primitive and shocking conditions in the mental institutions of his day and paving the way, with Dorothea Dix and others, for the founding of the first national organization for mental health. There was John Howard, among many others, in prison reform, and a host of men and women who pioneered in public education. In modern times, Eleanor Roosevelt was one of the first to recognize the importance of advocacy as a method of social change and rallied citizen support to improve the welfare of families in poverty, the ill, and the aged through legislation and other forms of political action.

To be sure, these and other heroic figures were dealing with major issues affecting large groups of people—not directly with individuals, as most of you will be doing—but they were all motivated in the first place by the plight of individuals who were submerged by a system they could not control. Back of every reform movement is an individual who has been a victim of injustice or neglect whose experience points to specific defects in society. Hence, in dealing with individuals who need protection and advocacy, you are working with the very basics of any reform movement. A reform that does not start with the individual, it has been said, does not start; and a reform movement that stops with the individual, stops. Thus, any individual problem that comes to your attention that appears to be a symptom of a larger problem, affecting many people rather than only a few, should be referred by you to appropriate advocacy systems for further attention.

The advocates of yesteryear to whom I have referred had certain qualities and skills in common that all modern advocates would do well to emulate. First, before they made a move to correct what appeared to be an act of injustice or neglect, they made sure they had the facts in hand; the facts, that is, on both sides of a controversy or complaint. And they sought to determine whether what they saw or heard was an isolated incident, an oversight, or a policy. Second, they were diplomats in the best tradition; they urged the perpetrators of a wrong to redress it on their own volition. They did not rock the boat or make waves to call attention to themselves; their purpose was to get results, not to make a scene. But when quiet and tactful methods failed, they drew up the big guns and launched a well planned and effective campaign, pulling no punches.

And third, though they were totally loyal to people in whose interests they were working, they did not allow that to blind them to the hard realities. For at times, their "clients" did not help their own cause and acted in ways that threatened the very goals they and their advocates sought; in such cases the advocates of the early days did not hesitate to let their clients know wherein they erred. And fourth, they did not do anything for their clients that they (the clients) could do, or could be helped to do, for themselves. These four qualities or skills plus the example of perseverance they gave us—they simply never gave up—constitute sound and sensible guidelines for advocates in the present day.

A Sense of Relatedness

No advocate can be effective working in a vacuum. The questions to be asked are: How does what I am doing relate to what others in the same general field in my community are doing? What can others do, as well or better than I? What can we do together? Advocates must be aware of the agencies, organizations, and individuals who can be of help to them. Many are needed if an advocate is to do more than a superficial job. In the first place, there are the developmental disabilities councils. It is both desirable and advantageous to work with and through them whenever possible. The more competent and knowledgeable people and organizations one can constructively involve in advocacy the better. Every time we enlist the help of others in carrying out our objectives, we have created an extension of ourselves and added to our effectiveness.

A Sense of Mission

Probably this needs less explanation than any of the four "uncommon senses" I am discussing. It is quite evident that most of you who are attending this conference feel a sense of commitment or mission or you would not be here. The opportunity to guide a child or an adult who is lost, discouraged, or desperate and to help him or her to find a way out of a morass of confusion and frustration is a privilege. To right a wrong in such a way as to give the victim of misfortune or injustice new hope and encouragement, and at the same time take steps to make it less likely that the same injustice will be perpetrated on others, is not only a public service of high order, but a mark of statesmanship.

Tommy Heinrich, the famous Yankee center fielder of many years ago, who was a philosopher as well as a fine athlete, used to say, "Catching a ball in the outfield is a pleasure; knowing what to do with it is a business." Thus, an advocate who not only helps to solve the problem of an individual in difficulty with the system but stimulates those who run the system to correct its shortcomings is performing an exceptional service.

Dag Hammerskjold, the late Secretary General of the United Nations, expressed in a very few words the essence of a true sense of mission. A motto on his desk read, "If not you, *who*? If not now, *when*?"

A Sense of Humor

Not all who have a sense of mission have the balance and perspective that is needed to make it human and warm and thus acceptable. Only those with the perspective a sense of humor brings can view the human condition with compassion and understanding and at the same time keep their sanity. There is a lesson for all of us in the story of the very earnest young man who went to work for a large, well known corporation. He had just finished an interview with his new boss and was starting for his new office when the boss called him back. "One more thing, Richard," he said, "don't forget Rule Six." "No sir," the young man responded, "but what is Rule Six?" "Don't take yourself too seriously," the boss replied. Richard smiled and asked, "What are the other five rules?" "They are all the same," the boss explained. "Just don't take yourself too seriously!"

There is the delightful story, and a true one, concerning A. J. Muste, for many years director of a unique organization known as The Labor Temple. The Temple was not a union, but rather a center devoted to the interests of all working people, particularly the poor. During the war in Vietnam, Mr. Muste made two trips to that country in the cause of peace though he was persona non grata to some of the ruling clique in that country. On his second trip he was deported and sent out to the airport in an open truck to await the next flight to the States. He was more than 80 years old at that time, and as he stood bareheaded in the burning sun, a group of young people who had made the trip with him crowded around him, solicitious of his health and welfare. Then, as one of his young followers told the story, Mr. Muste looked down on the worried faces turned to his, and with the perspiration running down his cheeks and his wonderful heart-warming smile illuminating his face, he reassured his followers as to his own condition and reminded them how fortunate they were to be able to take a stand for something vital in which they believed. "It's a wonderful life," he told them, "and I am a happy man." Perspective, forgiveness, no thought of self, and gratitude for

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the opportunity to serve: What a profound sermon he preached from the pulpit of the Vietnamese truck.

You are about to enter a testing period; for many of you it will be the first time you have been on your own in such a sensitive position with so much at stake. You will make mistakes, but they will not be of the heart, I am sure. You will fall down but you will learn as you get up and go on. Those of us who have met you here will be with you in spirit, and you have our best wishes, our confidence, and our faith.

Reports of Small Group Sessions

Reports of Small Group Sessions

Conference participants divided into groups of 15-20 persons at three times during the conference to discuss issues related to the protection and advocacy (P&A) systems. Reports of these sessions were compiled and are summarized below according to the topics discussed.

National Association of P&A Implementors

A national association of the P&A implementors could function as a clearinghouse for information exchange, offer technical assistance, help design and establish evaluation programs for P&A systems, give some national identity to the program, and serve as a liaison with other DD-related programs. Its chief function at present would be to serve as the communication link among P&A systems and as their collective voice on matters such as funding and legislation.

Some participants cautioned that an organization could enlarge the bureaucracy with which P&A systems must deal and that it could splinter P&A systems from other DD-related organizations. Another problem could be funding, as many states lack sufficient funds for fulfilling primary P&A functions.

A group of conference participants interested in an association met independently. While they formed no association, they agreed to select regional representatives to act as liaisons with other P&A implementors, to use the *Mental Disability Law Reporter* for information exchange, to coordinate their efforts in promoting favorable legislation, and to request a 1978 conference largely designed by P&A implementors.

Impending Developmental Disabilities Legislation

Concern focused on getting a bill passed in 1978 that would leave the developmental disabilities (DD) program intact instead of making it a part of another program such as vocational rehabilitation or welfare. Participants agreed that legislation should raise the authorization for P&A systems substantially, but many expressed the reservation that to push for the needed funds at this time would jeopardize the DD program. An alternative—the redistribution of DD funds, giving a larger share to P&A systems—was suggested.

Strategies for influencing the course of legislation were discussed, and the consensus was that P&A and other DD groups need a collective voice in Washington. To lobby independently would give the impression of fragmentation and would probably be self-defeating, given the present lack of sophistication of the P&A program regarding techniques of impacting on Congress.

Training

Neither volunteers, consumers, service providers, nor lawyers consistently have the training they need to conduct P&A effectively. All may lack basic knowledge of developmental disabilities; attorneys may not know the procedures for conducting hearings and using the court system. National sources of materials and information exchange would be useful, including a centralized library containing all available materials. Several states are developing their own training materials.

Suggested topics for inclusion in training materials are: discussion of the advocates' motivations; their responsibilities to the agency; their liability; the nature of professional assistance and the limits of action; how advocacy can be used; the interaction of professionals and consumers; policies set by agency boards; and how to record activities and report to the supervisor. It is important to include practice with formal training.

Resources

Foundations are an important source of funds for P&A systems. The following tips on getting foundation money were offered:

Seek the foundation's advice during the application process.

Make the supporting foundation visible by complimenting it around the state.

Offer the foundation a contigency: Get it to give you half the sum you need with the promise of your getting matching funds.

Develop a track record; prove your credibility.

Show the foundation that it is buying into a large project—that for every dollar it gives you, you will get four more.

Less conventional sources of support—money, facilities, and people—include: benefit performances; appeals to the business community; churches; direct mail or telephone solicitation; universities, clients; contracts for services with county MHMR boards; United Way; and members of Congress.

Problems with Implementing P&A Systems

Implementation of state P&A is inhibited primarily by inadequate fiscal resources. Particularly in minimum-allotment states, full implementation of the plan may not be possible.

Problems in interpretation of state P&A plans arise when implementors have had no input into the plan.

Matching volunteers to clients in terms of interests and available time and the high burn-out rate of one-to-one citizen advocates are some personnel problems.

Questions about the emphasis that the legal component should carry in the P&A plan have not all been resolved. Some state governments react negatively to the legal component. However, the capability to pursue litigation is a powerful means to an end.

The P&A experiment raises expectations that advocates can solve a variety of problems; if the systems do not fulfill these expectations, disappointment will result, threatening the existence of the P&A systems. Conversely, it is important to produce concrete results, but success could be self-defeating, as it would involve suing agencies funded by the same source that funds P&A systems, the Department of Health, Education, and Welfare.

Evaluation

Documentation of activities gives a P&A system credibility when it seeks funding. Evaluation also allows an agency to see whether it is meeting its goals and objectives and to modify parts of the program that are not functioning.

There is no one simple evaluation model. However, in addition to accounting for expenditures, P&A systems need information on caseloads, referrals and their sources, number of phone calls and letters, hours spent on each case, reasons for any changes in objectives, outcomes, and indication of follow-up. All evaluation systems should include client feedback.

Who should do the evaluation varies. Developmental disabilities councils can offer internal but not external evaluation. However, to put DD councils in the role of monitoring P&A systems could threaten their cooperative relationship. Other organizations which could provide evaluation are university affiliated programs, technical assistance systems, and the Economic Manpower Corporation.

To account to the public, P&A systems might provide monthly reports to private and public service agencies. Public awareness campaigns must include all disabilities.

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